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**Older adults' experiences of electroconvulsive therapy: An
interpretative phenomenological analysis**

AND

Clinical Research Portfolio

Volume I

(Volume II bound separately)

Claire Stewart

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
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October 2014

*Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology*



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Chapter One: Systematic Review

Effective components of life review and reminiscence
interventions for depressed older adults without dementia in
institutionalised care: a systematic review

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(See Appendix 1.1)*

ABSTRACT

Objectives: Depression is a major mental health concern affecting older adults. Prevalence rates are known to be higher within residential care facilities than in community samples. Depression results in an increased burden for both residents and staff attempting to provide care in residential care home settings. Therapeutic approaches including reminiscence and life review interventions have been trialed in care homes with some promising results. However, there are no systematic reviews specifically examining these interventions to identify their effective components. The current review aims to identify, synthesise and discuss key components of life review and reminiscence interventions for depressed older adults without dementia in institutionalised care. **Method:** A systematic literature search was conducted using Medline, Embase, PubMed, Psychology and Behavioural Sciences Collection, Psychinfo and CINAHL databases to identify relevant studies. Articles were screened against inclusion criteria. A narrative synthesis of relevant studies was undertaken. **Results:** Twelve studies met inclusion criteria. Seven studies were of 'low' quality, four were of 'moderate' quality, and one was of 'high' quality. **Conclusion:** reminiscence and life review interventions are effective for older adults without dementia and mildly cognitively impaired older adult patients with mild depressive symptoms. However, there is currently not enough evidence to be confident that those with moderate or severe depression would also benefit. Interventions are equally effective for male and female patients and increasing age also does not reduce the effects. Recommendations for clinicians are made.

Keywords: older adults; institutionalised care; depression; life review; reminiscence.

INTRODUCTION

With advances in medical technology life expectancy is increasing, contributing to an aging population worldwide. In 2005 adults over 65 years of age comprised 7.4% of the global population and this is projected to increase to 16.1% by the year 2050 (United Nations Population Division, 2009). It is estimated that in England there are more than 400,000 older people living in care homes (Care Quality Commission, 2012), with an additional 34,000 in Scotland (Reshaping Care for Older People, 2014). One of the major mental health concerns within older adult care is depression, which is a common and disabling disorder. Prevalence rates are known to be higher within care facilities than in community samples for both major depression and for depressive symptoms (Djernes, 2006). Katz and Parmelee (1997) summarised the literature regarding the impact of depression in care homes and reported that it is associated with increased: functional deficits, use of direct nursing staff time, reports of pain, and mortality rates. Given the growing number of older people in care homes, the higher prevalence of depression in this setting, and the serious consequences of this disorder, there is a clear need to provide more effective mental health care for this population.

Therapeutic approaches such as Cognitive Behavioural Therapy (CBT) (Pinquart & Sorensen, 2001), Behavioural Activation (Meeks et al., 2008), Problem-Solving Therapy (Ayalon et al., 2009), Reminiscence Therapy (Hsu & Wang, 2009), and Life Review Therapy (Haight et al., 1998) have been trialed in care homes with promising results. One systematic review (Bharucha et al., 2006) and two non-systematic literature reviews (Hyer et al., 2005; Powers, 2008) concluded that due to the poor quality of available literature there is only mild support for the efficacy of psychotherapy to reduce depressive symptoms in care home residents. A recent meta-analysis investigated the efficacy of psychotherapy on reducing depression in older adult care settings (Cody & Drysdale, 2013). The authors reviewed

randomised control trials (RCT's) of psychotherapeutic interventions used to treat depressive symptoms in care homes, including CBT, Reminiscence Therapy, Behavioural Activation, Self-worth Therapy and Therapeutic Conversation. The authors found a medium effect size indicating that psychotherapeutic interventions were effective in reducing symptoms of depression in residents. They concluded that psychotherapy may be a viable alternative to pharmacotherapy within care homes. However, they stated that the evidence base still needs to be clarified in order to be able to make formal clinical recommendations due to methodological weaknesses in the studies reviewed, including: small samples; lack of clearly defined depressive disorder; lack of manualised treatments and limited follow-up data.

The reviews discussed above examined the evidence in relation to psychotherapeutic interventions which encompass a variety of different approaches aimed at reducing depressive symptoms. Two of these therapeutic interventions, reminiscence and life review, have received particular interest from researchers in the field of older adults since Butler's (1963) article proposing that reviewing one's life is a central task of old age, and that it is an adaptive process facilitating acceptance and adjustment. Reminiscence is defined as the process of thinking or telling someone about past experiences that are personally significant (Pinquart & Forstmeier, 2012). Recently, Webster et al., (2010) distinguished between simple reminiscence and life-review. Simple reminiscence is described as mainly unstructured autobiographical storytelling with the goal of communicating with others, remembering positive past events, and enhancing positive feelings. Life-review is a more structured intervention, usually delivered in a one to one format and covers the entire life span. Here, the focus is on the (re-) evaluation of life events and on the integration of positive and negative life events into a coherent life story.

Evidence for the effectiveness of reminiscence and life review interventions has accumulated over the last decade. Several meta-analyses have concluded that reminiscence and life review are potentially effective treatments that improve well-being and

alleviate depressive symptoms (Bohlmeijer et al., 2007; Bohlmeijer et al., 2003). A recent comprehensive meta-analysis examining the effects of reminiscence interventions on psychosocial outcomes reported moderate improvements in depression and ego-integrity, with smaller effects on purpose in life, death preparation, mastery, mental health symptoms, well-being, social integration, and cognitive performance (Pinquart & Forstmeier, 2012). Most effects were maintained at follow-up. While these findings confirm the utility of these interventions for older adults living in the community, there has been little investigation into their effects within residential care settings.

Rationale for the current review

Although previous reviews (Bharucha et al., 2006; Hyer et al., 2005; Powers, 2008) and one meta-analysis (Cody & Drysdale, 2013) provided useful information regarding the efficacy of psychotherapeutic interventions to reduce depressive symptoms in care home residents, no reviews have been conducted specifically examining the literature in relation to reminiscence and life review interventions and their mechanisms of change. Although the meta-analysis by Cody and Drysdale (2013) did include studies that implemented reminiscence, all of the interventions investigated were grouped together as “psychotherapeutic interventions”. This does not allow clinically meaningful information regarding the content, delivery, or approach of specific interventions to be extracted; as different psychotherapeutic interventions are likely to have differing underlying mechanisms of change (for example affect regulation or development of a meaningful narrative). The Medical Research Council (MRC) developed guidance on developing and implementing complex interventions to increase the likelihood of interventions being disseminated into routine clinical practice (MRC, 2008). Within these guidelines, the importance of understanding an interventions components is emphasised, to enable its implementation within service delivery settings. Additionally, it has been recognised that the dissemination of empirically supported psychological interventions into clinical practice has been slow, and there is an identified need to improve this (McHugh & Barlow, 2010). It has been suggested that issues of effectiveness, change processes and

identification of the active components of interventions be considered in order to fit treatment development to the needs of clients, practitioners, and systems (Hayes, 2013). To do this, research findings must be translated into practical recommendations for clinicians.

Objectives

This systematic review aims to identify, synthesise and discuss key components of life review and reminiscence interventions for depressed older adults without dementia in institutionalised care (including care homes and long-term care facilities). This information will be used to make practical recommendations regarding the structure and delivery of these interventions in clinical practice.

Research Question

What are the components of effective reminiscence and life review interventions for depression among older adults without dementia in institutionalised care?

METHOD

Search Strategy

An electronic search was conducted on 21st March 2014 using the OVID, EBSCO and Web of Science on-line interfaces to identify relevant articles from the following databases: PubMed, Medline, EMBASE, Psychology and Behavioural Sciences Collection, Psychinfo, Web of Science Core Collection and CINAHL. The following search terms were used:

("life review" OR "life review therapy" OR "reminiscence")

AND

Depress*

AND

("institution*" OR "residential care" OR "care home" OR "nursing home")

Truncating (*) was used to ensure identification of relevant terms where word endings may differ. Searches were limited to papers published in English, and those testing participants over the age of 65. No date range limit was applied, so the search covered the complete range of each database.

Articles identified by the search strategy were screened using the following criteria:

Inclusion criteria

- Journal article published in a peer reviewed journal
- Written in English
- Studies involving a reminiscence or life review intervention
- Studies involving older adults (over 65 years of age) living in institutionalised care (including care homes and long-term care facilities)

- Studies involving older adults without dementia
- Studies that use a standardised and reliable outcome measure of depression (e.g. Geriatric Depression Scale, [Sheikh & Yesavage, 1986])
- Studies ensuring randomisation to a treatment condition versus a control condition

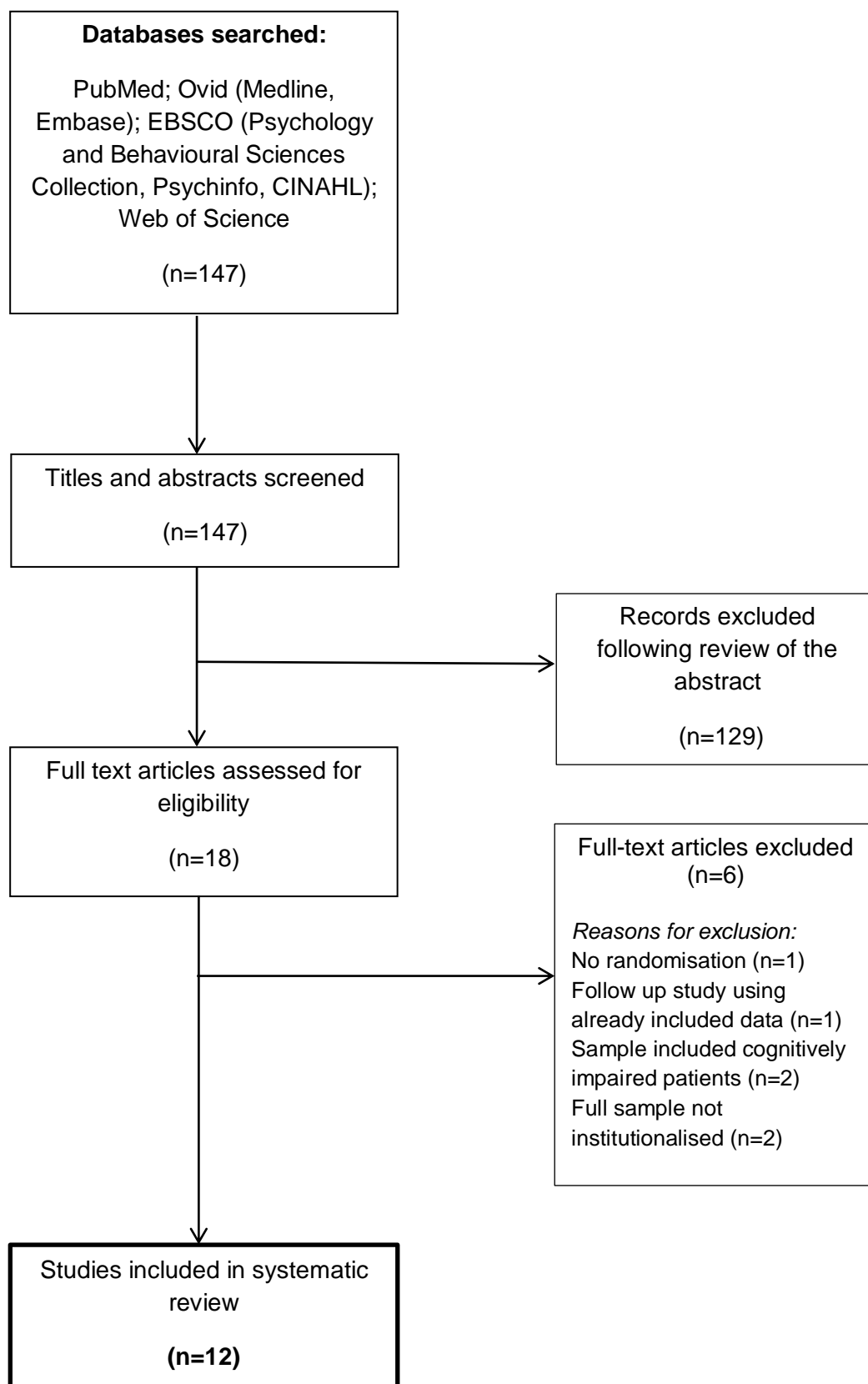
Exclusion Criteria

- Studies including participants with a diagnosis of dementia or participants classified as having cognitive impairment
- Review articles
- Books and book chapters
- Commentaries
- Case studies/reports/unpublished theses/policy documents

Outcome of search process

The search identified 147 articles. A total of twelve studies fulfilled criteria for inclusion in this review: Chaing et al. (2010); Chueh and Chang (2013); Cook (1991); Haight et al. (1998); Hsu and Wang (2009); Karimi et al. (2010); Melendez-Moral et al. (2013); Rattenbury and Stones (1989), Stinson and Kirk (2005); Wang (2005); Wu (2011) and Youssef (1990). Two papers included a mixed sample of those living in institutionalised care and those not living in institutionalised care. As data from those living in care was unable to be individually extracted, the papers were excluded. Had studies been identified that included a sample of those under and over 65 years of age, and the data for those over 65 years could not have been extracted, these studies would also have been excluded. Hand searching of the reference lists of the twelve papers yielded no additional articles. The process of study selection is illustrated below (Figure 1).

Figure 1: Flow diagram of study selection process



Data collection and quality assessment

The quality of all included studies was indexed using a modified version of The Clinical Trials Assessment Measure (CTAM) (Tarrier & Wykes, 2004). This is an assessment tool which can be used to estimate the quality of clinical trials. It has adequate internal consistency ($\alpha = 0.697$) and excellent external validity (Wykes et al., 2007). The original CTAM consists of 16 items covering six areas of trial design with a total score of 100. The CTAM was modified for this review (see Appendix 1.2) to ensure it was relevant to the studies included and to the investigation of intervention, patient and therapist characteristics. The modified CTAM consisted of an additional seven items (23 in total). The first additional item was concerned with whether the measure of depression was valid and reliable. This was added as it was considered important that the measures accurately represented levels of depression among the sample, and well validated and reliable measures increase confidence that this is the case. Additionally, well validated measures allow comparison across studies even when different measures are used. The second additional item questioned whether follow up of over 6 months was conducted. This was to enable assessment of whether improvements in depression scores were maintained longer term, or whether the intervention's effects were short term. This is important when considering the practical implementation of an intervention, for example whether it is delivered once or as part of a rolling program. The third asked whether there was a control group as it was considered important to ensure any reduction in scores was due to the intervention and not other variables. The fourth additional item questioned whether groups were similar at pre-test in order to ensure no other variables such as physical ill health, age or years of education could account for differences between groups at post-test. The fifth item asked whether an effect size calculation had been completed as it was considered important for studies to attempt to quantify the size of the difference between groups rather than simply report statistical significance. Again, this is important when considering the practical impact of an intervention within a clinical context. The sixth item questioned whether there was sufficient information provided to allow calculation of an effect size. This was added as

although some studies may not have reported effect size, they may have provided the information to allow this to be calculated, and this was considered to be of merit and deserving of additional points. The seventh item asked whether therapists were adequately trained. This was to allow more meaningful investigation into whether this therapist variable had an impact on outcomes, again an important consideration when implementing an intervention in a clinical context. Items added for this review were weighted according to their relevance to the research questions: 1 = low relevance, 3 = medium relevance and 5 = high relevance. The maximum score was 130. A percentage rating was calculated for each paper, with 49% or below considered 'low quality', 50 – 74% 'moderate quality', and 75 - 100% 'high quality'. These ratings were used to provide the author (CS) with an overall indicator for the level of confidence in which a particular study's findings could be taken.

To assess inter-rater reliability, 75% of the papers were also rated by a second researcher, a Doctorate of Clinical Psychology Trainee who was independent of the study. The agreement rate between researchers was high (98.7%) and any disagreement was resolved by discussion.

RESULTS

Quality of included studies

Methodological quality varied across the twelve studies, with scores ranging from 40 to 104 out of a possible 130 (Median: 60.5, Mean: 66.2) as measured by the modified CTAM. Six of the twelve studies were of 'low' quality, five were of 'moderate' quality, and one was of 'high' quality. A summary of the quality ratings for all studies included in this review is provided in Table 1. A summary description of all studies included in this review is provided in Table 2.

Table 1: Summary of quality rating of included studies

Study	Total out of 130	% Rating	Quality rating
Haight et al. (1998)	104	80%	High
Karimi et al. (2010)	83	63.8%	Moderate
Rattenbury & Stones (1989)	79	60.7%	Moderate
Chaing et al. (2010)	72	55.4%	Moderate
Chueh & Chang (2013)	61	53.1%	Moderate
Hsu & Wang (2009)	66	50.1%	Moderate
Wu (2011)	60	46.2%	Low
Wang (2005)	58	44.6%	Low
Youssef (1990)	58	44.6%	Low
Cook (1991)	57	43.8%	Low
Melendez-Moral et al. (2013)	56	43.1%	Low
Stinson & Kirk (2006)	40	30.7%	Low

Table 2: Summary description of study characteristics

Study	CTAM Score (%)	Sample characteristics	Intervention characteristics	Therapist characteristics	Depression outcome measure	Measure of cognitive function	Conclusions	Effect size (depression)
<i>High quality studies</i>								
Haight et al. (1998)	80%	Cognitive status: orientated to person, place & time (measured by the MSQ). Sample size: 201. Control groups n=97, intervention groups n=104. Male n=62, female n=139. Mean age=79.6. Homogeneity: Groups homogenous on all demographic variables and outcome measures except for age.	RCT. Control groups: received a friendly visit equal in time to LR visits. Intervention: individualised LR in 1 hour sessions weekly for 6 weeks. Total sessions n = 6. (Two control groups and two experimental groups). Techniques: Structured by the LREF. Topics included childhood and home, adulthood and summary sessions.	Qualifications & training: “therapeutic listeners” – skilled interviewers trained in the use of LR.	DIS BDI	No measure	Depression scores were significantly improved after a 6 week LR intervention compared to controls. This benefit was maintained at 1 year follow up.	BDI Between groups Intervention vs. control: Post treatment: d = 0.14 1 year: d = 0.19 Within groups Unable to calculate
<i>Moderate quality studies</i>								
Karimi et al. (2010)	63.8%	Cognitive status: MMSE > 21. Sample size: 29. Control group n=10, intervention (integrative) n=10, intervention	RCT. Control group: active social discussion group. Intervention: instrumental or integrative reminiscence group. All groups met weekly for 6 weeks and	Qualifications: Masters level therapist supervised by Clinical Psychologist led all 3 groups.	GDS – SF (Iranian version)	MMSE (Iranian version)	In comparison to an active control group, depression symptoms in the integrative reminiscence	Not reported and unable to calculate.

		<p>(instrumental) n=9. Male n=12, female n=17. Mean age = 70.5.</p> <p>Homogeneity: Groups homogenous on depression severity and gender (systematically divided into 3 groups and then randomly assigned to intervention), but other demographics not reported.</p>	<p>sessions were 90 mins. Total sessions n=6.</p> <p>Techniques: Instrumental – stress & coping framework including coping resources, primary and secondary appraisal strategies, and problem- and emotion-focused coping responses. Integrative – cognitive re-attribution framework including disconfirmation of negative beliefs about the self and the future; alternatives to self-blame; evaluation of self-worth; and renewed sources of self-worth. 6 different themes used in both. Homework to think about memories for next topic.</p>	<p>Training: no additional training reported. Manual by Watt & Cappeliez (2000) used.</p>			<p>group demonstrated a statistically significant reduction. In comparison to the control group, depression symptoms in the instrumental reminiscence group did not demonstrate a statistically significant change. No follow-up data.</p>	
<p>Rattenbury & Stones (1989)</p>	<p>60.7%</p>	<p>Cognitive status: "free from obvious cognitive impairment". Sample size: 24. Control group n=8, reminiscence group n=8, current topics group n=8.</p> <p>Homogeneity: Groups homogenous on baseline scores on outcome measures but demographics not reported.</p>	<p>RCT. Control group: no treatment control. Intervention: reminiscence group and current topics discussion group. 8, 30 min sessions held over 4 weeks (2 per week). 4 participants per group (treatment groups each divided into 2 sub-groups). Techniques: reminiscence group -</p>	<p>Qualifications: all sessions conducted by a Clinical Psychology graduate specialising in gerontology, and a registered nurse with experience of working with older adults.</p>	<p>MUMS</p>	<p>Not measured</p>	<p>A significant effect was found on MUNSH scores for both intervention groups compared to the no treatment control group. No significant effects were found on MUNAI, MUMS</p>	<p>Not reported and unable to calculate.</p>

			topics included childhood experiences, adolescence, work; World War II; the Depression; technological advances; marriage and late adulthood. Current topics group asked to discuss topics as viewed today (no reference to the past).	Training: no additional training reported.			or SGRS scores. No follow up data.	
Chaing et al. (2010)	55.4%	Cognitive status: MMSE > 20 (mild or no cognitive impairment). Sample size: 92. Control group n=47 Intervention group n=45, male n=92, female n=0. Mean age = 77.2. Homogeneity: Groups homogenous on baseline characteristics (educational level, marital status, self-perceived health status, economic status and number of chronic medical illnesses, and baseline scores on outcome measures.	RCT. Control group: waiting list control. Intervention: structured group reminiscence therapy for 8 weeks (once per week for 90 mins). Total sessions n=8. Techniques: structured sessions focusing on a different topic every week.	Qualifications: Masters level student in mental health nursing with experience in older adults lead groups, co-leader extensive experience in group and reminiscence therapy. Training: 54hr didactic training (provided by the author) and use of therapy manual.	CES-D	MMSE	Reminiscence therapy improved depressive symptoms, psychological well-being and feelings of loneliness at post-test and 3 month follow up.	CES-D Between groups Post treatment: Reminiscence vs. control: d= 1.1 Follow up: Reminiscence vs. control: d= 1.89 Within groups Pre vs. post: Reminiscence: d= 1.4 Pre vs. follow up: Reminiscence: d=1.8

Chueh & Chang (2013)	53.1%	<p>Cognitive status: SPMSQ > 8. Sample size: 21. Control group n=10, intervention group n= 11, male = 21, female n=0. Mean age = 82.</p> <p>Homogeneity: Groups homogenous on baseline characteristics (age, educational level, marital status, self-perceived influence of chronic diseases on daily living, eye cataracts) and baseline scores on outcome measures.</p>	<p>RCT. Control group: waiting list control. Intervention: group reminiscence therapy for 4 weeks (twice a week for 60 mins). Total sessions n=8. Techniques: structured sessions focusing on a different topic every week. Wars; increasing expression of feelings about forced displacements; positive relationships; life stories; life transitions; personal accomplishments and goals; positive strengths and a review of all sessions.</p>	<p>Qualification & training: facilitator had extensive experience and training in group counselling and rem therapy.</p>	GDS (Taiwan version)	SPMSQ	The study results demonstrate that reminiscence therapy significantly improved participants' depressive symptoms. Improvements maintained at 3 and 6 month follow-up.	Not reported and unable to calculate.
Hsu & Wang (2009)	50.1%	<p>Cognitive status: MMSE > 17 for illiterate and >21 for those with 6 or more years education. Sample size: 45. Control group n=2. Intervention group n=24, male n=24, female n=21. Mean age = 77.9.</p> <p>Homogeneity: Groups homogenous on baseline characteristics (age, gender, educational level,</p>	<p>Experimental design. Control group: no treatment. Intervention: reminiscence group with 8-10 participants. 8, 60 min sessions held weekly. Techniques: topics selected included "first meeting," "childhood experiences," "old time flavour of food," "old time music," "festival," "my family," "when I was young," and "my award". Food,</p>	<p>Qualifications: Groups facilitated by two masters level geriatric nurse specialists with expertise in reminiscence therapy. Training: Each had an additional 16 hours of group therapy training.</p>	GDS-SF (Chinese version)	MMSE	Data used for those who completed 6-8 sessions used for analysis. A 6 to 8 week group reminiscence intervention significantly improved depression and behavioural competence.	<p>GDS-SF (Chinese version)</p> <p>Pre vs. post: d= 1.03</p>

		marital status, number of medications used, length of stay in institution, economic status and number of chronic medical illnesses) and baseline scores on outcome measures. Completers: 8 sessions n= 15, 7 sessions n=22, 6 sessions n=2.	photos, and recordings of old songs were used to stimulate conversation.					
<i>Low quality studies</i>								
Wu (2011)	46.2%	Cognitive status: MMSE > 24. Sample size: 74. Control group n=39, intervention n=35. Male n=74, female n=0. Mean age = 81.3. Homogeneity: Groups homogenous on baseline characteristics (age, educational level, marital status, self-reported health status or number of chronic diseases) and baseline scores on outcome measures.	RCT. Control group: TAU. Intervention: structured group integrative reminiscence therapy weekly 1 hour sessions for 12 weeks. Total sessions n=12. Techniques: 12 themes: introduce myself; a past photo I missed; a memorable trip; a memorable person; a proud thing in life; present life; one thing I can do now and hope for the future. Participants encouraged to review and conclude past events. Songs, documents and pictures used to evoke memories.	Qualifications: not specified. Training: states research team was trained and given practical guidelines but no further information on these.	GDS-SF (Chinese version)	MMSE	Group integrative reminiscence revealed immediate effects on improving the self-esteem and life satisfaction of institutionalised older veterans, and depressive symptoms were also decreased. No follow up data provided.	GDS-SF (Chinese version) Between groups Post treatment: Reminiscence vs. control: d= 0.98 Within groups Pre vs. post: d= 1.01

Youssef (1990)	44.6%	<p>Cognitive status: not reported. Sample size: 60. Control group n=21, 2 intervention groups stratified by age. Intervention group (74 and under) n=21, intervention group (75 and over) n= 18. Male n= 0, female n=60. Mean age (74 and under) = 67.5, (75 and over) = 77.8.</p> <p>Homogeneity: Groups homogenous on marital and financial status, and baseline scores on outcome measures.</p>	<p>RCT. Control group: met only for pre and post measures. Intervention: group rem counselling, 45 min sessions, held twice during first week and once per week for remaining 5 weeks. Total sessions n=7.</p> <p>Techniques: first 2 topics selected by investigator (non-threatening e.g. holidays, food preparation), other 4 selected by participants. Photographs and scrapbooks used to encourage rem.</p>	Not reported.	BDI	Not measured	Depressive symptoms were significantly improved following intervention for elderly women 74 years and under. Depressive symptoms did not significantly improve in those 75 years and over. No follow up data.	Not reported and unable to calculate.
Cook (1991)	43.8%	<p>Cognitive status: “no mental impairment” as determined by the MSQ. Sample size: 54. TAU control group n=18, current events control group n=18, intervention group n= 18, male =18, female n=36. Mean age = 81.3. Homogeneity: Groups homogenous on age, length of time in the nursing home and baseline scores on outcome measures but differed on gender and</p>	<p>Experimental design. Control group: no treatment, met only for pre and post measures. Current events control group and intervention: group met for 1 hour once a week for 16 weeks. Total sessions n=16.</p> <p>Techniques: structured. Focused on pleasant memories. Sessions designed to focus on each decade and included childhood experiences, marriage,</p>	Not reported.	GDS	MSQ	No significant differences between groups on post-test scores of depression. No follow up data.	Not reported and unable to calculate.

		educational level.	family life, and jobs. Old pictures, recordings of old songs etc. were used to evoke memories and provide stimulation. Asked to keep a journal of memories between sessions but most of the participants were noncompliant.					
Meléndez-Moral, et al. (2013)	43.1%	Cognitive status: MMSE > 23. Sample size: total sample n= 34, n for control group and intervention group not reported. Gender breakdown not reported. Mean age = 79. Homogeneity: Groups homogenous on baseline characteristics (age, gender, educational level and marital status) and baseline scores on outcome measures.	RCT. Control group: TAU (activities provided by care home). Intervention: 8, 60-min group sessions held. Total sessions n=8. Techniques: structured, each session focused on a theme: from childhood through old age; remembering where I've lived: my town/city; games from childhood; popular songs; holidays and special days; the movies; and remembering my grandmother.	Qualifications: a psychologist conducted the group sessions. Training: not reported.	Mini-GDS 8 GDS - SF	MMSE	Significant results were obtained, including a drop in depressive symptoms and improved self-esteem, satisfaction, and psychological well-being. No follow up data reported.	Not reported and unable to calculate.
Wang (2005)	40.8%	Cognitive status: "no obvious cognitive impairment". Sample size: 48. Control group n=23, intervention n=25. male n=29, female n=19. Mean age = 75.9. Homogeneity: Groups	RCT. Control group: no treatment control. Intervention: unstructured individual reminiscence. Groups met weekly over period of 4 months for 30-45 mins. Total sessions n=16. Techniques:	Qualifications: 3 researchers (no stated qualifications) Training: 2 month reminiscence training course performed by	GDS-SF (Chinese version) AER (additional measure of depressed mood –	Not measured	Depressive symptoms of participants in the experimental group decreased significantly and their mood status improved	GDS-SF (Chinese version) <u>Between groups</u> Post treatment: Reminiscence

		homogenous on baseline characteristics (age, gender, educational level, marital status, living arrangements, and economic status) and baseline scores on outcome measures.	participants encouraged to recall past events. Topics such as childhood experiences, marriage, family life, war, and jobs were included. Old photos, recordings of old songs etc. were used to evoke memories and stimulate conversation.	principal researcher (PhD in the field of gerontological care and experience conducting rem therapy)	observer scale)		compared to that of the controls.	vs control: d= 0.62 <u>Within groups</u> Pre vs post: d= 0.48
Stinson & Kirk (2006)	30.7%	Cognitive status: no significant cognitive impairment as determined by staff in care facility. Sample size: 24. Control group n=12, intervention group n=12. Male n=1, female n=23. Complete data obtained for n=17 (control group n=7, intervention n=10). Homogeneity: Not reported.	RCT. Control group: TAU. Intervention: structured reminiscence group sessions held twice weekly for 6 weeks, 60 min sessions. Total sessions n=12. Techniques: intervention not described.	Qualifications and training: not reported.	GDS	Not measured	No significant differences in depression and self-transcendence found between the reminiscence group and control group at the completion of a six week intervention.	Not reported and unable to calculate.

Abbreviations:

BDI	Beck Depression Inventory (Beck & Beamesderfer, 1974)
CES-D	Centre for epidemiological studies depression scale (Radloff, 1977)
CSDD	Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988)
GDS	Geriatric Depression Scale (Yesavage et al., 1983)
GDS-SF	Geriatric Depression Scale – Short Form (Sheikh & Yesavage, 1986)
	Chinese version (Chan, 1996)
	Iranian version (Malakouti et al., 2007)
	Taiwan version (Liao, 2004)
LR	Life Review
LREF	Life Review and Experiencing Form
	Chinese version (Huang and Chung, 1987)
Mini-GDS 8	Mini Geriatric Depression Scale (Buz, 1996)
MMSE	Mini-mental state examination (Folstein, Folstein & McHugh, 1975)
MSQ	Mental Status Questionnaire (Khan, 1960)
MUMS	Memorial University Mood Scale (McNeil, 1986)
NIC	Nursing Interventions Classification (McCloskey & Bulechek, 1996)
SGRS	Stockton Geriatric Rating Scale (Meer & Baker, 1966)
SPMSQ	Short Portable Mental State Questionnaire (Pfeiffer, 1975)

The objective of this review is to investigate the components of effective reminiscence and life review interventions for depression among older adults without dementia in institutionalised care. This section will synthesise information from the studies, structuring the results using the following headings - patient characteristics, intervention characteristics, and therapist characteristics.

Patient characteristics

Sampling Method

Eight studies recruited from nursing homes (Chaing et al., 2010; Cook, 1991; Haight et al., 1998; Hsu & Wang, 2009; Karimi et al, 2010; Rattenbury & Stones; Wang, 2005; Youssef, 1990), two from veterans nursing homes (Chueh & Chang, 2013; Wu, 2011) one from retirement homes (Melendez-Moral et al, 2013) and one from an assisted living facility (Stinson & Kirk, 2005). In four studies, participants volunteered to take part (Youssef, 1990; Stinson & Kirk, 2005 Rattenbury & Stones, 1989; Chueh & Chang, 2013). Two studies (Hsu & Wang, 2009; Wang, 2005) selected residents meeting inclusion criteria and invited them to participate. Three studies (Wu, 2011; Cook, 1991; Karimi et al., 2010) identified all residents within the care home meeting eligibility criteria then randomly selected a sample and invited them to participate. One study (Haight et al. 1998) randomly selected residents from lists provided by staff, screened them and if identified as eligible, invited them to participate. Although these latter four studies also used volunteers, they randomly selected a sample from those meeting eligibility criteria, which was an attempt to increase the representativeness of the sample. Two studies did not report how their sample was obtained (Melendez-Moral et al., 2013; Chaing et al, 2010).

Sample size

Total sample size across studies ranged from 21 (Chueh & Chang, 2013) to 201 (Haight et al., 1998). No studies reported performing power calculations to determine an appropriate

sample size. Only three studies (Haight et al., 1998; Chaing et al., 2010; Wu, 2011) recruited more than the recommended minimum sample size of 27 participants per group (Tarrier & Wykes, 2004). After accounting for attrition rates, these three studies were still above this minimum number for analysis at post-intervention and follow-up. The remaining nine studies had between eight (Rattenbury & Stones, 1989) and 25 participants per group (Wang, 2005).

Cognitive status

Five studies measured cognitive status using the MMSE (Karimi et al., 2010; Chaing et al., 2010; Wu, 2011; Hsu & Wang, 2009; Melendez-Moral et al., 2013), three used the MSQ (Haight et al., 1998; Chueh & Chang, 2013; Cook, 1991), and three used no measurement tool, relying on clinical judgement to detect cognitive impairment (Rattenbury & Stones, 1989; Wang, 2005; Stinson & Kirk, 2006; Youssef, 1990). Classification of 'no cognitive impairment' using MMSE scores ranged from cut off scores of >17 (for illiterate participants in the Hsu & Wang (2009) study) to >24 (Wu, 2011).

Age and gender

The mean age of participants ranged from 67.5 years (the 'younger' group in the Youssef, (1990) study) to 82 years (Cheuh & Chang, 2013). All studies but two (Rattenbury & Stones, 1989; Melendez-Moral et al., 2013) reported the gender of participants. Of these studies, three (Chaing et al., 2010; Chueh & Chang, 2013; Wu, 2011) consisted of purely male participants and one consisted of purely female participants (Youssef, 1990). One study (Stinson & Kirk, 2006) reported a small number of male participants (4%). The remaining five studies reported a roughly equal gender split ranging from 31% male to 63% male.

Depressive symptoms

Nine studies provided information on the severity of participants' depressive symptoms at baseline. However, only two of these studies (Hsu & Wang, 2009; Karimi et al., 2010)

required that participants were depressed to be eligible for the study. These studies were both of moderate quality. Four however, reported mean pre-test scores and standard deviations that would indicate their total sample was at least mildly depressed before intervention (Chaing et al., 2010; Chueh & Chang, 2013; Haight et al., 1998; Wu, 2011). All but one of these studies (Wu, 2011) were also of moderate quality. The remaining three studies reported that their sample was mixed, with some participants meeting criteria for depression, and some scoring within a normal range (Wang, 2005; Stinson & Kirk, 2005; Youssef, 1990). These three studies were classified as low quality. Three studies (Cook, 1991; Melendez-Moral et al., 2013; Rattenbury & Stones, 1989) did not state whether their sample was depressed and did not report mean scores so this could not be determined.

Intervention characteristics

Type and delivery of therapy

Eleven studies delivered reminiscence interventions. One study (Haight et al, 1998) delivered life review therapy. Ten studies delivered the intervention in a group format (Chaing et al., 2010; Chueh & Chang, 2013; Cook, 1991; Hsu & Wang, 2009; Karimi et al., 2010; Melendez-Moral et al., 2013; Rattenbury & Stones, 1989; Stinson & Kirk, 2005; Wu, 2011; Youssef, 1990), and two used individual formats (Haight et al., 1998; Wang, 2005). The number of participants in the intervention group ranged from four (Rattenbury & Stones, 1989) to twelve (Stinson & Kirk, 2006), however, most studies conducted intervention groups with 8-10 participants per group (Karimi et al., 2010; Hsu & Wang, 2009; Chueh & Chang, 2013; Wu, 2011; Cook, 1991). Three studies only reported total sample size and did not specify the size of each intervention group (Chaing et al., 2010; Youssef, 1990; Melendez-Moral et al., 2013). All but four studies reported that sessions were delivered weekly. Within these four, three studies reported delivering the intervention twice per week (Rattenbury & Stones, 1989; Chueh & Chang, 2013; Stinson & Kirk, 2006). Session length ranged from 30

minutes (Rattenbury & Stones, 1989) to 90 minutes (Karimi et al., 2010), although most lasted around 60 minutes. The number of sessions conducted ranged from six (Haight et al., 1998; Karimi et al., 2010) to 16 (Wang, 2005), but it was most common to have between six and eight sessions, which was reported by eight studies (Haight et al., 1998; Karimi et al., 2010; Rattenbury & Stones, 1989; Chaing et al., 2010; Hsu & Wang, 2009; Chueh & Chang, 2013; Youssef, 1990; Melendez-Moral et al., 2013). As can be seen, the interventions delivered in the studies reviewed showed variations in session length, frequency of sessions, number of sessions and the ratio of patients to therapists. Therefore, despite all purporting to be delivering a similar intervention (with the exception of Haight et al., 1998 who delivered a life review intervention) they do not appear to be delivered in a consistent way using a specified manual or protocol.

Content of intervention

Of the eleven studies delivering reminiscence interventions, nine described their intervention simply as “reminiscence” rather than specifying a particular type (Rattenbury & Stones, 1989; Chaing et al., 2010; Chueh & Chang., 2013; Hsu & Wang, 2009; Stinson & Kirk, 2006; Melendez-Moral, 2013; Wang, 2005; Youssef, 1990; Cook, 1991). All nine studies describe this as a structured intervention focusing on a different topic each session. These topics vary widely between studies; but include examples such as childhood, working life, a memorable trip, wars, family life, and ‘old time’ food. The remaining two studies delivering reminiscence interventions did specify the type of reminiscence used, one stating delivery of both instrumental and integrative reminiscence in two separate groups (Karimi et al., 2010), and one delivering integrative reminiscence (Wu, 2011). Integrative reminiscence is implemented within a cognitive re-attribution framework and the following strategies are used: disconfirmation of negative beliefs about the self and the future; alternatives to self-blame; internal guidelines for the evaluation of self-worth; and renewed sources of self-worth. Both studies used this framework. The intervention strategies in the instrumental reminiscence

intervention are implemented within a stress and coping framework and included: coping resources, primary and secondary appraisal strategies, and problem- and emotion-focused coping responses. Five studies reported the use of food, photos, scrapbooks, and recordings of old songs to stimulate conversation and evoke memories (Hsu & Wang, 2009; Wu, 2011; Wang, 2005; Youssef, 1990; Cook, 1991). However, all but one (Hsu & Wang, 2009) was low quality. Only two studies stated a manual was used to guide intervention (Karimi et al., 2010; Chaing et al., 2010), and one stated the Life Review and Experiencing Form (LREF) was used (Haight et al., 1998). All studies that used a manual were rated as moderate or high quality. One study reports the use of 'practical guidelines' but no further information regarding what these consist of was provided (Wu, 2011). None of these studies addressed issues of therapist adherence to protocol. The remaining eight studies did not report the use of manuals or guidelines.

Control groups

All studies included a control group. In the majority of studies, this consisted of a treatment as usual or a waiting list control group. However, three studies (Haight et al, 1998; Karimi et al. 2010; and Rattenbury & Stones, 1989) attempted to account for non-specific treatment effects by providing a 'friendly visit' (Haight et al, 1998) an 'active social discussion group' (Karimi et al., 2010) and a 'current topics discussion group' (Rattenbury & Stones, 1989). These control groups received the same level of therapist contact as the intervention groups.

Main findings

All but three studies (Rattenbury & Stones, 1989; Cook, 1991; Stinson & Kirk, 2006) found depressive symptoms were reduced following intervention. Karimi et al., (2010) found reduction in depressive symptoms following the integrative reminiscence group, but not following the instrumental reminiscence group. Only one study (Hsu & Wang, 2009) reported effect sizes. Four studies (Chaing et al., 2010; Haight et al., 1998; Wu, 2011; Wang, 2005)

provided data to enable these to be calculated. The seven remaining studies did not report data to enable effect sizes to be calculated.

Maintenance of post-intervention gains

Only three studies provided follow up data. Haight et al., (1998) found that the benefit of their intervention was maintained at one year follow up, Chaing et al., (2010) reported that reduction in depressive symptoms was maintained at three month follow up, and Chueh and Chang (2013) reported that improvements were maintained at three and six month follow up.

Attrition rates

Seven studies reported attrition rates ranging from 20% (Haight et al., 1998) to 31% (Chaing et al., 2010). In studies that provided information on attrition rates for both control and intervention groups, the number of participants dropping out was similar. However, three studies (Wu, 2011; Chueh & Chang, 2013; Youssef, 1990) report much lower attrition rates, ranging from 0% (Chueh & Chang, 2013) to 9% (Youssef, 1990). Two studies (Melendez-Moral et al., 2013; Rattenbury & Stones, 1989) did not report attrition rates or provide the data to allow these to be calculated. Many studies claim that participants found the intervention enjoyable, that it allowed residents access to social support and gave them a sense of meaning; however no studies collected any quantitative or qualitative data evaluating participants' experiences of the intervention.

Therapist characteristics

Qualifications

Five studies provided details of the level of qualification of those involved in delivering interventions. Three studies rated as moderate quality used mental health professionals

educated to masters level as facilitators (Karimi et al, 2010; Chaing et al, 2010; Hsu & Wang, 2009), one study, also rated as moderate quality had a Clinical Psychology graduate as facilitator (Rattenbury & Stones, 1989), and one study rated as low quality had a clinical Psychologist (Melendez-Moral et al., 2013). Seven studies did not provide information on the level of qualification of those delivering interventions. Six of these studies were rated as low quality, one was rated as high.

Experience and training

Three low quality studies did not provide information on the experience and training of those delivering interventions (Stinson & Kirk, 2006; Cook, 1991; Youseff, 1990). Of the remaining nine studies, five moderate quality studies reported that group facilitators had experience of either working with older adults, or of delivering life review or reminiscence interventions (Karimi et al., 2010; Rattenbury & Stones, 1989; Chaing et al., 2010; Chueh & Chang, 2013; Hsu & Wang, 2009). One high quality study used 'therapeutic listeners' who are described as skilled interviewers trained in the use of life review interventions (Haight et al., 1998), and two low quality studies trained the research team to deliver the interventions but no information is provided about their experience or qualifications (Wu, 2011; Wang, 2005). Five studies provided additional training specifically related to the delivery of reminiscence or life review interventions (Chaing et al., 2010; Hsu & Wang, 2009; Wu, 2011; Wang, 2005; Haight et al., 1998). Only one study (Karimi et al., 2010) reports the use of supervision. No studies provided information regarding how therapist competence was determined, and none performed competency checks throughout delivery of the intervention.

DISCUSSION

What are the components of effective reminiscence and life review interventions for depression among older adults without dementia in institutionalised care?

Patient characteristics

Most studies recruited volunteers who may represent a particularly motivated sample compared to the general population, and most samples were recruited from only one residential facility. Both these factors limit the generalisability of findings to the wider population and reduce confidence that the improvements in mood demonstrated by the majority of studies (nine) would still apply in routine clinical practice. Three studies did not find an improvement in depressive symptoms. Two of these studies did not use a measure of cognitive status, relying on clinical impression to determine presence of cognitive impairment. This may mean inclusion of cognitively impaired participants, who may have struggled to participate due to their cognitive difficulties, which may explain the lack of significant findings. However, two of these studies were rated as low quality, and one was moderate quality so it is likely that other methodological limitations contributed to this, such as small sample sizes and low scores on baseline measures of depression. Further support that the lack of significant findings in these studies was unrelated to the inclusion of cognitively impaired participants comes from examination of the studies that did measure cognitive status. These studies used inconsistent cut off points for 'no cognitive impairment', ranging from a score of >17 to a score of >24 on the MMSE. This means some samples may actually be classified as mild or moderately impaired. Despite this, the majority of studies found that the interventions were effective; indicating that despite the inclusion of patients with scores indicating mild levels of cognitive impairment, reminiscence and life reviews interventions did reduce depressive symptoms.

All studies reviewed reported the age of their participants, and the mean ranged from 67.5 years to 82 years. Youssef (1990) reported that depressive symptoms significantly improved in the 'younger' group (74 and under) but not in the 'older' group (75 and over). In addition, their sample was all female. This finding may suggest that 'older' female patients do not benefit from reminiscence and life review interventions. In support of this, the sample in the Stinson and Kirk (2006) study also contained a majority of female participants (96%) and also did not find a reduction in depressive symptoms. However, the Youssef (1990) and Stinson and Kirk (2006) studies are both rated 'low' quality, so it is not possible to be confident in these conclusions. Additionally, the mean age of the 'older' group in the Youssef (1990) study was 77.8 years which is equivalent to the age of participants in other studies which did find significant benefits post-intervention. The weight of the evidence from this review would indicate reminiscence and life review interventions are equally suitable for reducing depression in 'older' and 'younger' older adults in institutionalised care. Additionally, four of the five studies that reported a roughly equal gender split found significant reduction in depressive symptoms, indicating reminiscence and life review interventions are equally effective for male and female participants.

This review is concerned with reduction in symptoms of depression. Of the nine studies that reported the severity of participants' depressive symptoms at baseline, only six reported that their sample met the diagnostic criteria for depression. Four studies from this six measured depressive symptoms using the GDS (various language versions) and the remaining two used the BDI and the CES to measure severity of depression. These are all well validated measures of depression, and the GDS in particular has been developed for use in an older adult population. The remaining three studies reported their sample was mixed, comprising those meeting criteria for depression and those not clinically depressed. Samples containing participants who are not clinically depressed make it difficult to generalise these findings with confidence to clinical populations. Two of the three studies not to find a reduction in

depressive symptoms did not state whether their sample was depressed, and did not report mean scores to allow this to be calculated. If their samples were not depressed at baseline, then there is limit to the amount of positive change that can be achieved at post-test, and it therefore becomes more difficult to identify significant change using statistical methods. Additionally, of the six studies with participants meeting diagnostic criteria for depression, four included participants in the mild range of depression. Only two studies reported their sample was out with the mild range of severity. Therefore, it is possible that the positive results reported may only be applicable to those with mild depressive symptoms. It is also important to note that none of the studies reported change of diagnostic status, instead using a continuous measure of depressive symptoms. This may dilute the therapeutic effects of the intervention due to issues such as diagnostic overlap of depressive symptoms. Also, although reduction in depression scores may be statistically significant, it may not translate into clinically significant change. For example, in the Hsu and Wang (2009) study, post-test scores would still place some participants within the 'depressed' range (mean 7.9, SD 1.7) on the GDS-SF. From the results of this review, it is only possible to conclude that reminiscence and life reviews interventions are effective for those in institutionalised care with mild depressive symptoms. More research needs to be conducted to investigate whether they are still effective at reducing depression in moderately and severely depressed institutionalised patients.

Overall, it can be tentatively concluded that reminiscence and life review interventions are effective for older adults without dementia and mildly cognitively impaired older adult patients with mild depressive symptoms. Age also does not appear to reduce the effects of these interventions, and they appear equally effective for male and female patients. However, there is currently not enough evidence to be confident that those with moderate or severe depression would also benefit due to lack of research in this population.

Intervention characteristics

Nine studies found a reduction in depressive symptoms and these included interventions in a group and individual format. However, as only two studies delivered interventions in an individual format the conclusions that can be made about the effectiveness of individual interventions in institutionalised care is limited. It is interesting to note however, that despite one of these studies being 'low' quality (the other was 'high' quality) both found significant improvements in depressive symptoms. The remaining ten studies utilised a group format, and the majority had eight to ten participants per group, met weekly for six to eight weeks and sessions lasted approximately 60 minutes. Significant improvements in depressive symptoms were found in all but one (Cook, 1991) of the studies that followed this format. Three studies reported running groups twice weekly, but two of the three (Rattenbury & Stones, 1989; Stinson & Kirk, 2006) failed to find a reduction in depressive symptoms. As the Rattenbury and Stones (1989) study is of moderate quality, this may indicate twice weekly sessions are not beneficial. In addition, their failure to find significant effects may also be related to a short (30 minute) session length. However, it is not possible to be confident in these conclusions given the limited number of studies employing this format. Given the importance of delivering interventions in a cost effective and time efficient manner, it is beneficial to implement an intervention that consumes the least time while still providing therapeutic improvement. Based on the findings from this review, it would seem appropriate to utilise a group format of between six and eight sessions, containing eight to ten participants per group, where possible, rather than more time consuming and costly individual interventions.

All the studies delivering group reminiscence interventions describe the intervention as structured, focusing on a different topic each week. As topics vary widely between studies, and still find significant improvements in depressive symptoms, it appears that it is the process of reminiscence that's important rather than the specific content of the topic. The

results from this review would suggest that topics should be designed to facilitate and optimise the likelihood of discussion among participants. Reminiscence involves autobiographic storytelling which is thought to activate a social function (Westerhof et al., 2010). The sharing of common experiences should therefore promote this function and result in a positive impact on mood. Additionally, due to the close association between autobiographical memory and the development of identity, reminiscence may give participants the opportunity to develop a greater understanding of themselves and their life histories, resulting in the formation of a coherent sense of self and identity (Conway, 2005). Reviewing the past may also result in the resolution of unresolved conflicts, allowing them to be reintegrated into a coherent life narrative (Butler, 1963). It is proposed that the activation of the social function of reminiscence, the opportunity to re-evaluate one's life and identity, and to resolve conflicts, results in the benefits seen following reminiscence and life review interventions (Westerhof et al., 2010). Developing topics related to commonly significant periods of time or themes in life such as childhood, working life, family life, war time etc. facilitates discussion among participants and should result in these processes being activated. Several studies developed topics using their knowledge of the group members, for example, a veterans group included a 'war time' topic (Chueh & Chang, 2013). Additionally, common topics are likely to promote non-specific group effects including interaction with other group members, shared experiences and the development of friendships which all have a positive impact on mood.

Wong & Watt, (1991) found that two specific types of reminiscence, integrative reminiscence and instrumental, were found to correlate with successful aging. Two studies included in this review, one of moderate (Karimi et al., 2010) and one of low quality (Wu, 2011), reported beneficial effects of integrative reminiscence, but no effect of instrumental reminiscence was found. However, due to the very limited evidence available for these types of interventions in

institutionalised care, it is not possible to draw any firm conclusions regarding this population at present.

While the studies reviewed here indicate group reminiscence interventions did reduce depressive symptoms, it is important to consider that nine of the studies did not control for non-specific treatment effects such as provision of a meaningful activity, social cohesion, peer support and the development of friendships. Haight et al., (1998) compared their intervention to an 'active social discussion' group, and although they still reported significant results, their effect size was a lot smaller ($d=0.14$) compared to other studies that used a 'treatment as usual' control group. However, this effect size is not unusual in psychological treatment studies and it is known that effect size is typically inversely related to trial quality which may explain the smaller effect size in this high quality study. Additionally, although the Rattenbury and Stones (1989) study was rated moderate quality, they did not find a reduction in depressive symptoms. This may be due to their inclusion of a 'current topics discussion' group. The use of comparable control groups that deliver equitable level of contact time to the intervention group is important when assessing the efficacy of interventions as it may be that the improvement in depressive symptoms is due to group factors rather than the interventions themselves. Although it can be concluded that life review and reminiscence interventions are effective in reducing symptoms of depression in institutionalised care, future research should investigate their efficacy when compared to groups controlling for non-specific effects. This will allow for more confident conclusions that the active components of the interventions are the reminiscence and life review processes rather than the non-specific group processes.

Only three studies reported follow up data, but all three reported that gains were maintained. One high quality study found the benefit was maintained at one year follow up, and two moderate quality studies reported maintenance at three and six month follow up. This

provides preliminary evidence that the effects of the intervention are durable, and is in line with findings reported in a recent meta-analysis (Cody and Drysdale, 2013). However, several previous investigations have demonstrated that the improvements seen after reminiscence interventions had more of a short-term effect (Goldwasser et al., 1987; Tadaka & Kanagawa, 2004). More longitudinal research is needed to determine whether treatment should be a time-limited intervention or part of a continuous and on-going program to sustain patient functioning.

Attrition rates above 15% are considered high (Tarrier & Wykes, 2004). Rates in the majority of studies reviewed were around 20 – 31%, which may be an indication that patients did not find the intervention acceptable. However, where information on attrition rates for both control and intervention groups was provided, the number of participants dropping out was similar. This may indicate high attrition rates are to be expected due to the nature of the population under investigation, rather than the interventions being unacceptable. As this review focuses on studies with participants who are not cognitively impaired, they are likely to be in a care facility due to a physical health difficulty. They are therefore more likely to be frail, have physical health problems, and be admitted to hospital more frequently. In support of this, common reasons reported for not completing the intervention include: being unable to comply with the therapy schedule; health problems; relocation to another institution; being hospitalised and death. In addition, three studies report low attritions rates (under 10%) which supports the acceptability of the interventions. Many studies claim that participants found the intervention enjoyable; however, no studies actually collected quantitative or qualitative information evaluating participants' experiences of the intervention, so it is difficult to determine this definitively.

Therapist characteristics

In studies where qualifications were stated, those delivering interventions tended to be mental health professionals educated to at least masters level. However, the majority of studies (seven) did not report qualifications so it is not possible to make any recommendations regarding a necessary level of qualification for facilitators. Studies tended to focus on the professional experience of the facilitator and most studies reported experience of either working with older adults, or of delivering life review or reminiscence interventions. Five studies that found significant effects described providing additional training specifically related to the delivery of the interventions but only two used a protocol or manual to guide intervention. Of the two studies that did, neither addressed issues of therapist adherence to protocol. However, despite this, beneficial effects were found in the majority of studies. Some authors suggest that staff need basic skills in facilitating the process of spontaneous reminiscence and promoting social interaction, which may indicate specialist skills and training is not necessary (Westerhof et al., 2010). However, based on the available evidence from these studies, it is not possible to make a recommendation regarding a necessary level of qualification for facilitators, nor to conclude whether it is necessary to provide specific training or use a manual or protocol to deliver the intervention.

A summary of the supporting evidence for each characteristic is reported in Table 3.

Table 3: Summary of study characteristics and supporting evidence

Overall Characteristic	Specific Characteristic	Summary of evidence
Patient characteristics	Cognitive impairment	Equal efficacy for those without dementia and those mildly cognitively impaired
	Age	Equal suitability to reduce depression in 'older' and 'younger' older adults
	Gender	Equal efficacy for male and female participants
	Severity of depressive symptoms	Effective for mild depressive symptoms Unclear whether also effective for moderate and severe depression
Intervention characteristics	Group versus individual	Group format is effective Individual interventions may be effective but are more time consuming and costly
	Topic selection	Topics should facilitate discussion Specific content of topic not important
	Types of reminiscence	Not enough evidence to recommend integrative and instrumental reminiscence interventions
	Follow up	Preliminary evidence indicates effects are maintained at follow up However, more longitudinal data is needed
Therapist characteristics	Facilitator qualifications	Not possible to make a recommendation regarding a necessary level of qualification for facilitator
	Facilitator training	Unknown whether it is necessary to provide specific training Unknown whether a manual or protocol should be used

Suggestions for future research

Future research should draw their sample from multiple residential facilities in order to increase the generalisability of their findings and provide more evidence that these interventions can be successfully applied in routine clinical practice. Further research is needed to investigate whether reminiscence and life review interventions are effective at reducing depressive symptoms in moderately and severely depressed patients in institutionalised care. Additionally, consideration should be given to the clinical significance of change, perhaps by utilising Quality of Life (QOL) measures and reports of diagnostic change to evidence the impact on the participant's life. Additional research on the efficacy of individually delivered interventions would be helpful for those unwilling or unable to participate in group interventions. Studies completed with community participants have found integrative and instrumental reminiscence are particularly correlated with successful aging, and two studies in this review found beneficial effects for integrative reminiscence. It would be important for future research to investigate these interventions further in an institutionalised sample to determine whether they would be equally as beneficial among this population. It may be that those in residential care may need more tailored interventions due to illness severity and physical health comorbidities, but further research could help determine this. Future research should also ensure that interventions are compared to control groups controlling for non-specific effects to strengthen the assertion that the active components of the intervention are the reminiscence processes rather than non-specific group processes. There is limited evidence regarding the long term effects of these interventions and future research should address this by conducting longitudinal research to determine whether treatment should be a time-limited intervention or part of a continuous programme. Finally, future studies should collect quantitative and qualitative information to evaluate participants' experiences in order to determine the acceptability of the interventions to enable the dissemination of these in routine clinical practice. As has been observed by the

MRC, acceptability of an intervention is a key consideration when conducting research as this will impact on ability to implement interventions in routine clinical practice (MRC, 2008).

Strengths and limitations

This study is the first to systematically review the components of reminiscence and life review interventions for depression among older adults without dementia in institutionalised care. Only studies from peer-reviewed publications were included in this review which introduced a potential publication bias in the findings. Additionally, the search strategy only included studies in English which has the potential to introduce bias as relevant studies from non-English speaking countries may have been excluded. The exclusion of studies including participants with a diagnosis of dementia or cognitive impairment may also limit the generalisability of the findings of this review to residents of institutionalised facilities as there are high rates of patients with dementia in such settings. The review used a recognised quality assessment tool in order to identify methodological weaknesses present in the available literature. However, the criteria used for methodological evaluation are open to subjective interpretation and there is a possibility of biased results, despite the use of an independent rater.

Conclusions and recommendations for clinicians

Overall, it can be tentatively concluded that reminiscence and life review interventions are effective for older adults without dementia and mildly cognitively impaired older adults with mild depressive symptoms in institutionalised care. However, there is currently not enough evidence to be confident that those with moderate or severe depression would also benefit. Interventions are equally effective for male and female patients and ‘younger’ and ‘older’ older adults.

Based on the findings from this review, several recommendations can be made to facilitate implementation of these findings into clinical practice:

- There is currently not enough evidence to specifically recommend integrative reminiscence or instrumental reminiscence
- It is appropriate to utilise a group format (where possible) of between six and eight sessions containing eight to ten participants per group
- If a group format is not possible, there is limited evidence to suggest individual interventions are also beneficial to reduce depressive symptoms
- It is not possible to conclude whether it is necessary to provide specific training or use a manual or protocol to deliver interventions, but sessions should be structured using topics likely to stimulate discussion and social engagement
- Topics should be developed using knowledge of the group members, e.g. a veterans group including a 'war time' topic
- A QOL rating scale used in addition to a valid and reliable measure of depression (e.g. the GDS-SF) will provide clinically relevant improvement data
- Quantitative and/or qualitative information evaluating participants' experiences of the intervention should be collected to determine acceptability

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Chapter Two: Major Research Project

Older adults' experience of electroconvulsive therapy: An
interpretative phenomenological analysis

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***Submitted in partial fulfilment of the requirements for the degree of
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Appendix 2.1)*

ABSTRACT

Background: Electroconvulsive therapy (ECT) is prescribed in cases of severe and treatment resistant depression. Its efficacy in reducing depressive symptoms is well established, but due to uncertainty regarding its impact on cognitive functioning, remains one of the most controversial treatments in psychiatry. The experiences of patients undergoing ECT are rarely examined, and studies that have investigated this are generally conducted with younger adults using quantitative methods that may obscure the expression of complex attitudes. **Aims:** The present study investigates older adults' experiences of ECT in Scotland using a qualitative methodology. **Methods:** Four older adults (over 65 years of age) who had experienced ECT within the last five years were interviewed. Interpretative Phenomenological Analysis (IPA) was used to explore participants' experiences of ECT. **Results:** Three superordinate themes emerged from the data: experience of depression, power and control, and changing beliefs about ECT. **Conclusions:** Recommendations are made for clinicians and healthcare providers. 1) Information about ECT should be provided in an oral format on a one to one basis, 2) medical professionals should be alert to the possibility of coercion, 3) action should be taken to reduce anticipatory anxiety regarding ECT's potential impact and 4) meeting patients for up to two sessions after undergoing ECT may be beneficial. These recommendations can be used to contribute to existing improvements in delivery of care and treatment for older adults receiving ECT.

Keywords: electroconvulsive therapy, ECT, older adults, IPA, subjective experience

LAY SUMMARY

Electroconvulsive Therapy (ECT) is a psychiatric treatment in which seizures are electrically induced in patients with the aim of improving low mood. It is used for severely depressed patients who do not respond to antidepressant medication or psychological therapy, and research has shown that it can produce fast and effective results. Most research has looked at whether ECT works, how it works, whether there are any lasting side effects and how best to administer it. This is valuable information; however, the experiences of patients undergoing ECT have rarely been investigated. Previous studies have focused on younger adults, and little is known about how older adults make sense of having ECT and the effect it has on them. The current research investigated older adults' experiences of receiving ECT in Scotland. Four older adults (over the age of 65) who had received ECT in the last five years were interviewed. It was possible to group what the participants said into three main themes that related to their experience of ECT. **Theme 1:** Experience of depression, **theme 2:** Power and control, and **theme 3:** Changing beliefs about ECT. Four recommendations are made for clinicians and healthcare providers: 1) patients should be spoken to about ECT before treatment on a one to one basis, 2) medical professionals should make sure patients don't feel pressured to have ECT, 3) medical professionals should try and reduce anxiety about the effects patients may believe ECT will have on their memory and personality and 4) meeting with patients for up to two sessions after ECT may be helpful. These recommendations can be used to contribute to existing improvements in delivery of care and treatment for older adults receiving ECT.

INTRODUCTION

Electroconvulsive therapy (ECT) is recommended in cases of severe, life threatening depression that has not responded to multiple pharmacological treatments or psychological therapy (NICE, 2009). Many studies have shown that for patients resistant to medication, ECT shows fast and effective results with 85% – 90% efficacy compared to 60% – 65% efficacy for antidepressant medication (Nobler & Sackeim, 2001; Shergill & Katona, 2001). Specific research with older adults generally suggests that ECT reduces depression faster and with fewer negative physical effects than other methods of treatment (Kelly & Zisselman, 2000; McCartney, 2000). Despite this, ECT remains one of the most controversial treatments in psychiatry. One of the main concerns repeatedly raised in relation to ECT is whether it results in persistent cognitive impairment. Reviews of studies measuring cognition post-ECT in younger adults generally indicate that detrimental effects on concentration, sustained attention, orientation, the retention of newly learned information and the retention of information learned before treatment tend to resolve three to six months following treatment completion (Ingram et al., 2008; Semkovska & McLoughlin, 2010). However this does not appear to be the case for autobiographical memory (Verwijk et al., 2012). Findings are less conclusive for older adults as research into the cognitive effects of ECT remains limited and conflicting due to methodological weaknesses such as small sample size, lack of controls, use of a single screening instrument and a short follow up period (Tielkes et al., 2008; Gardner & O'Connor, 2008).

Most research to date has focused on investigating aspects of ECT such as efficacy, dosage, mode of administration, cognitive effects and mechanism of action. This is valuable information and has revolutionised the administration of ECT, however, there is little research exploring the complexities of how patients make sense of their experience of ECT and the meaning it holds for them (Chakrabarti, Grover & Rajagopal, 2010). Research

throughout the 1980's and early 1990's did attempt to address this, asking patients to respond to questions or complete checklists about their attitudes to and experience of ECT (Freeman & Kendall, 1980; Malcolm, 1989; Riordan et al., 1993). The majority of people questioned found ECT helpful but most reported side-effects, with memory impairment as the most frequent complaint. Interestingly, most people report that ECT is not frightening to receive. However, most previous studies used quantitative approaches, attempting to categorise experiences and attitudes by comparing frequency of positive and negative answers. In relation to this research, Rose, Fleischmann and Wykes, (2004) argued that people's beliefs about their experiences and their social world are complex, and that reducing patients' perspectives on ECT to simple attitude measures does not capture the richness and complexity of experience. They recommend that qualitative methods be used to explore in detail how patients make sense of their experience and the meaning that the experience holds.

In a recent review of 75 quantitative and qualitative studies conducted among the elderly, adolescents, and young to middle-aged adults, Chakrabarti et al., (2010) investigated patients' knowledge and perceptions of ECT. They found that patients reported: fear of ECT; were usually poorly informed about ECT; described experiencing distressing side effects following ECT; and around one-third reported feeling coerced into having the treatment. Despite this, they also reported that the vast majority of patients perceived ECT to be helpful and had positive views regarding the treatment. Qualitative studies tend to report similar themes, including: feelings of coercion into undergoing ECT and feelings of powerlessness during the consent process (Fisher et al., 2011; Johnstone, 1999; Orr & O'Connor, 2005; Smith et al., 2009); a lack of information regarding the risks and procedure of ECT (Fisher et al., 2011; van Daalen-Smith, 2011; Smith et al., 2009; Johnstone, 1999); and a fear of ECT (Johnstone, 1999; Koopowitz et al., 2003). Additionally, several studies report significant cognitive problems and/or autobiographical memory losses after ECT (Johnstone, 1999;

Koopowitz et al., 2003; Rose et al., 2004; Smith et al., 2009). In a review of quantitative and qualitative clinician and service-user led research, Fisher (2012) discussed findings from an unpublished qualitative dissertation examining the experience of patients who reported autobiographical memory loss following ECT (Hecquet, 2008). The study found that participants were distressed by their memory loss and this impacted on their sense of self. Hecquet (2008) reported participants had difficulties adjusting to their lowered self-confidence as they tried to actively make sense of their treatment, themselves and their lives. This observed impact on identity was also reported in a study that specifically recruited participants who described ECT as a distressing or traumatic experience (Johnstone, 1999). In addition to themes including shame and humiliation, fear, worthlessness, helplessness and a sense of having being abused and assaulted, some participants reported losing aspects of their life histories which they felt negatively impacted on their sense of self.

Although the literature appears to reflect a move towards qualitative investigations of patients' experiences of ECT, the majority of studies consider its effects among younger adults, and there is currently very little research investigating older adults' experiences. However, one study has explored this topic with older adults, interviewing six older women about their experiences of ECT (Orr & O'Connor, 2005). The authors identified a central theme of power shifting to others, leading to a sense of disconnection and distancing from the experience. The authors also noted that the women's narratives were saturated with medical discourse, and hypothesised that their experiences were shaped by the medical social context due to a lack of other available ways to interpret or develop an understanding of their experiences. They attributed this to the "closeted nature of depression and ECT within all but the medical community" (Orr & O'Connor, 2005, pp.33).

Rationale for the current study

It is important to understand how older adults experience ECT, as research shows those over 65 in developed countries receive a disproportionately high share of ECT compared with younger adults (Chanpattana, 2007; Wood & Burgess, 2003; Department of Health, 1999). Studies have consistently estimated that 24% to 50% of patients receiving ECT are older adults (Chanpattana 2007). There may be differences between younger and older adults' experiences of ECT due to cohort differences based on maturing in a specific historical time period, developmental maturation and greater life experience. These factors are likely to play an important role in the perception of an experience and in the meaning constructed from that experience. Additionally, since 2009, the Scottish ECT Accreditation Service (SEAN) have been striving to improve the standards of care in ECT in Scotland and have developed national standards based on various good practice statements (The Royal College of Psychiatrists Centre for Quality Improvement, 2011; NHS Quality Improvement Scotland, 2003; NICE, 2003) and person centred measures of quality taken from a national SEAN audit completed in 2000 (CRAG Working Group on Mental Illness, 2000). Accreditation visits are carried out on all clinics delivering ECT in Scotland, and all have made significant improvements to the provision of care when delivering ECT (Scottish ECT Accreditation Network Annual Report, 2013). It is important to interpret the findings of this study within this context, as these changes to the provision of care in ECT may have an impact on patients' experiences of undergoing the procedure.

Aims

The aim of the current study was to explore older adults' experiences of receiving ECT in Scotland using a qualitative approach. The use of a qualitative research methodology was considered to be most appropriate to exploring these experiences, as qualitative methods aim to develop a detailed understanding of participants' perspectives (Elliott, Fischer & Rennie, 1999).

METHOD

Design

Qualitative research focuses on understanding how people make sense both of their world, and the experiences they have within their world (Merriam, 2009). Specifically, Interpretative Phenomenological Analysis (IPA) combines a desire to understand the 'lived' experience of the participant with a belief that interpretative work on the part of the researcher is required in order to achieve this (Smith & Osborne, 2008). IPA offers a systematic way of approaching this task where each case is examined in detail as an entity in its own right, before a narrative account is developed summarising general themes evidenced by detailed extracts from individual participant accounts (Smith, 2011). Recently, Smith (2011) identified several core features of a high-quality IPA study. These included establishing a clear focus, having strong data derived from good quality interviews, well evidenced and elaborated themes, strong interpretative commentary, and demonstration of convergence and divergence of themes. IPA has been identified as particularly useful where the topic under investigation is dynamic, contextual and subjective, relatively under-studied and where issues relating to identity, the self and sense-making are important (Smith, 2004). IPA was considered the most appropriate choice as the current study meets all these identified criteria.

In accordance with IPA methodology, purposive homogeneous sampling was utilised (Smith, Flowers & Larkin, 2009). This involves selecting participants because they have particular features or characteristics that will enable detailed exploration of the phenomena being studied, rather than selecting a random sample. This is thought to facilitate greater understanding into the phenomena under study.

Recruitment

Prior to commencing recruitment, ethical approval for the study was obtained from the West of Scotland Research Ethics Committee (Appendix 2.4). As it was envisaged that the potential pool of participants would be small, Research and Development Management Approval was obtained for both NHS Lanarkshire and NHS Ayrshire & Arran (Appendices 2.2 and 2.3). Recruitment took place between January and June, 2014. Participants were recruited through Old Age Psychiatrists, ECT nurse practitioners, and clinicians in older adult Community Mental Health Teams (CMHT's). These clinicians were asked to identify potential participants from their caseloads. The inclusion and exclusion criteria are detailed below.

Inclusion Criteria

- Aged over 65 and have received ECT at least 6 months ago, but no longer than 5 years previously
- English speaking (due to interviewer and interpreter constraints)

Exclusion Criteria

- Significant current mental health difficulties or symptoms of dementia which impact upon functioning, and would prevent meaningful participation in or ability to consent to an interview (determined by the clinical judgement of the referring clinician)
- Have verbal communication difficulties that would prevent participation in an interview (determined by the clinical judgement of the referring clinician)

A total of four participants agreed to take part in the study. All those interested in participating were provided with a participant information sheet containing further details of the study (see Appendix 2.6). Those who gave permission for the principal researcher to contact them were contacted by telephone to address any questions or concerns they have

about participating. Following this, an interview was arranged for those who agreed to participate.

Participants

29 potential participants who met inclusion criteria were identified. Several potential participants (n=7) were deemed unsuitable to approach by clinicians involved in their care (psychiatrists or community psychiatric nurses) due to physical illness, development of a dementia or worsening of their depressive symptoms requiring inpatient care. Several participants were approached by clinicians involved in their care, but decided against taking part in the study (n=11). The main reason cited for this was wishing not to revisit the experience of ECT as it was regarded as a negative or traumatic experience (n=8). The remaining participants (n=7) did not respond to the letter of invite so it is not known why they did not wish to participate. Four agreed to participate in the current study. This is within the recommended sample of between four and ten participants for Doctoral research studies employing IPA (Smith et al., 2009). Additionally, saturation of themes was noted after completion of four interviews, and the decision was made to stop recruitment at this point. All participants were female, aged between 69 and 87 years of age. Gender appropriate pseudonyms were assigned to maintain anonymity. A summary of participant characteristics is shown in Table 1 below.

Table 1: Participant characteristics

	Mary	Judith	Anne	Maggie
Age	73	80	69	87
Date of ECT	June 2013	April 2013	Aug 2013	Nov 2013
Number of courses of ECT	1	1	2	2
Presenting Problem	Depression	Depression	Depression	Anxiety and depression

Procedure

Interviews were held in an outpatient clinic room on NHS premises within the participants' locality. Each interview was recorded and transcribed verbatim. Written consent (see Appendix 2.7) was obtained prior to commencing the interviews which included consent to record the interview and publication of anonymised quotations. A semi-structured interview schedule was developed (see Appendix 2.8). Interviews were conducted in a flexible manner, using open ended questions with further probes and specific questions as required, to encourage participants to elaborate on important topics. Throughout the interview, an emphasis was placed on establishing rapport and trying to understand the participants perspective. Empathic communication skills such as active listening, acknowledgement, validation, and summarising were used to facilitate this process. Participants were encouraged to talk as broadly as possible about their experiences of ECT and their views on this treatment. Participants were also encouraged to discuss how they made sense of their experience and reflect on whether this experience impacted upon their sense of self or their identity. The first interview was reviewed by the supervising researcher and the principal investigator to ensure the schedule elicited the required information. No changes to the schedule were deemed necessary following this review. The length of interviews ranged between 29 minutes and 54 minutes (average 47 minutes). All interviews were transcribed verbatim and anonymised by the principal investigator, with identifying information removed.

Data analysis

IPA was used to analyse the transcripts. This methodology consists of a number of recognised stages (Smith et al., 2009). Firstly, each transcript was read repeatedly, allowing the principal researcher to become familiar with the account. Next, descriptive, linguistic and conceptual notes were made in the right hand margin to begin to identify patterns of meaning. Emergent themes were developed within the transcript by mapping the interrelationships, connections and patterns between these exploratory notes (see Appendix

2.9). Thematic connections were then identified within the transcript in order to develop a list of superordinate and sub-themes that most accurately represented the participants' narrative. This process was repeated for each transcript. Once themes had been identified in individual transcripts, overarching themes were identified across all transcripts by considering patterns, similarities and differences between accounts. To validate inter-rater reliability of the themes identified, a secondary rater (an experienced qualitative researcher supervising the project) independently rated three of the four transcripts. Discussion of emergent themes identified a high level of agreement.

Researcher reflexivity

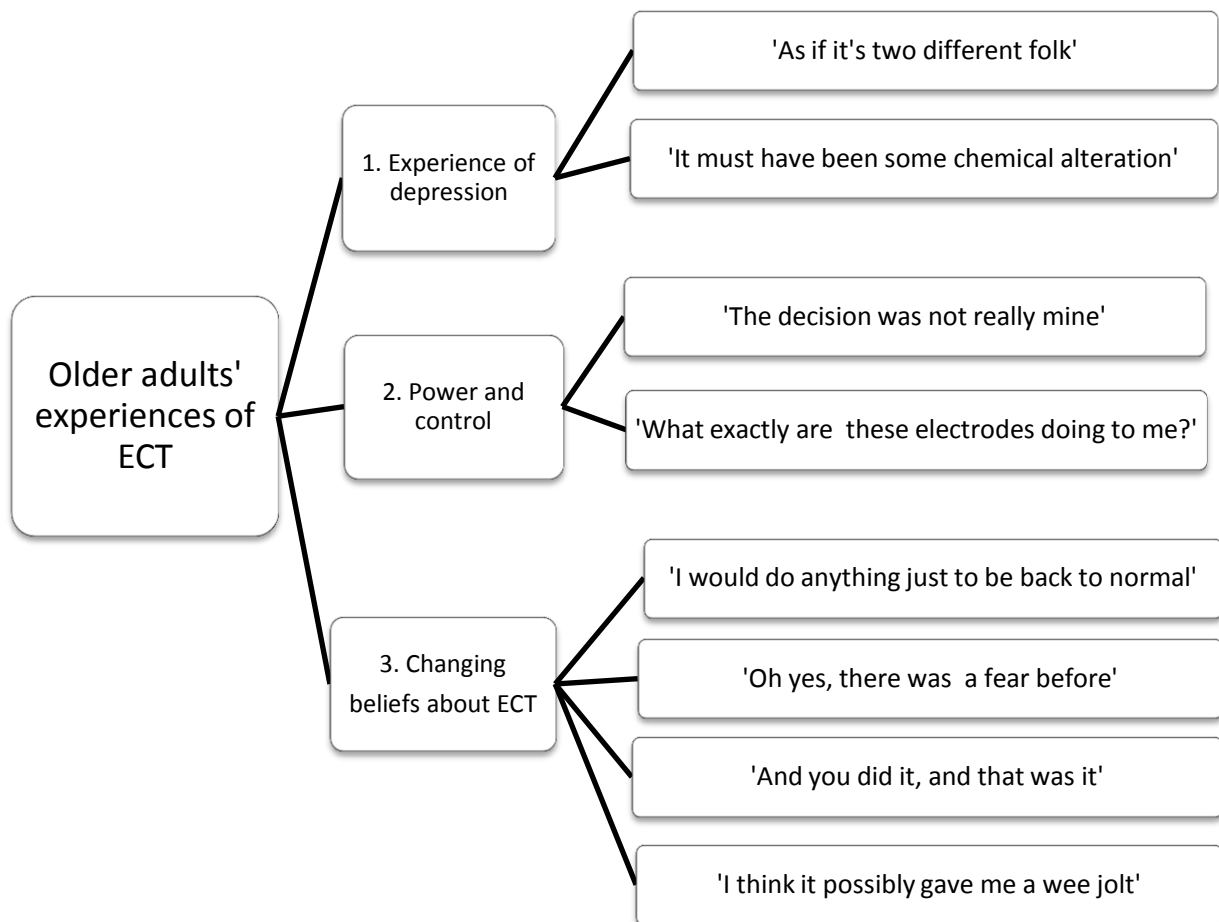
Within IPA, it is explicitly recognised that the researcher's own beliefs and assumptions will influence how they interpret and make meaning from the participant's account. The IPA researcher is therefore encouraged to reflect on their own views during the data gathering and analysis stages to increase awareness of sources of bias that may be brought to analysis (Smith, et al., 2009). Toma et al., (2003) recommend attempting to get as close to the participant's experience as possible in order to enhance understanding of this experience. To address this, the principal researcher visited the ECT suite and observed the procedure in person, allowing her to reflect on the thoughts and feelings this evoked for her. She acknowledged through this reflection that she perceived the procedure to be strongly clinical, that is, carried out in a heavily medical context. She noted a lack of collaboration and discussion with the patient regarding the procedure which evoked a sense of shock and frustration for her. As the interviews progressed, she was also aware that her training in clinical psychology was causing her to generate an alternative formulation of the interviewees' difficulties. This led to feelings of frustration as she wondered whether psychological therapy had been considered before treatment with ECT. Reflecting on these issues prior to and during the analysis process helped to maintain a balanced and open-

mindful approach. Regular discussion with the supervising researcher also facilitated reflection and acknowledgment of possible assumptions and sources of potential bias.

RESULTS

Three superordinate themes concerning the participants' experiences of ECT emerged from the interviews. These were labelled *experience of depression, power and control and changing beliefs about ECT*. Quotations from the participants have been used to label each sub-theme as this was felt to best represent the true meaning behind each theme. Extracts from individual participants accounts have been selected to provide supporting evidence for each theme. Table 2 (see Appendix 2.10) lists superordinate themes, associated sub-themes and details of extracts used to illustrate each theme. Taken out of context, some extracts appear to begin with leading questions or statements from the interviewer; however, these are follow-up questions to a statement previously made by the interviewee. Prior sections of text have only been excluded for the sake of brevity. Participants often referred to the medical professionals involved in their care by name therefore names have been changed to their job title in order to preserve confidentiality. A model of the emergent themes is illustrated in Figure 1.

Figure 1: Model of emergent themes



In addition to the three superordinate themes identified, participants' experiences of attending follow-up sessions were considered. Follow-up sessions consisted of meeting with an ECT nurse following treatment. At these meetings, participants completed a number of cognitive assessments with the nurse, and were given feedback regarding their performance. The assessments consisted of an objective measure of cognitive functioning (Addenbrooks Cognitive Examination – Revised, [Mioshi et al., 2006]) and a mood state measure (Montgomery-Asberg Depression Rating Scale, [Montgomery & Asberg, 1979]). Additionally, a subjective measure of cognitive functioning was administered which asked participants to rate performance in each cognitive domain using a self-report scale. This was

supported with a semi-structured clinical interview focusing on frequency, onset and on obtaining examples of reported difficulties. These sessions also provided an informal environment for participants to ask questions about their treatment and discuss any concerns they had. This opportunity existed for some participants because the health board where they received treatment (Ayrshire & Arran) was interested in assessing cognitive functioning after the procedure.

Theme 1: Experience of depression

Although the main focus of this study was exploring participants' experiences of receiving ECT, it became clear that this experience could not be understood without considering it within the broader context of their experience of depression. This superordinate theme consists of two sub-themes: *'As if it's two different folk'* and *'It must have been some chemical alteration'*.

As if it's two different folk

When asked whether ECT had had an impact on their identity, all participants expressed the idea that it was depression rather than ECT that had a significant impact on their identity, somehow removing the 'real them' and creating two different selves. This was conceptualised by participants as the 'depressed me' and the 'real me'. This is illustrated by the following quote from Anne:

Interviewer: "So, if you think about yourself before you had the ECT [when you were depressed] and yourself now, is that the same person?"

Anne: "I don't think so. I think it's two different, uh-huh, just as if it's two different folk."

(Anne, pg 7, lines 258 – 260)

This idea of two separate selves is further emphasised by Anne. Although she was asked about the effects of ECT on her identity, she discussed the effects depression had on her:

Interviewer: "So it sounds like the depression really affected how you saw yourself, so you weren't the person that you had been before, but the ECT doesn't seem to have affected how you see yourself? Does that make sense?"

Anne: "Uh, yeah, it just helps, you think you're, eh, sort of, what would you say... thinking not a great deal about yourself, you know, your confidence and everything, and you wonder what, what's the real me, kind of thing, that's the bit and I got, I was wee bit kind of worried that the better part of me, was that a different kind of person? Or was I more like the depressive one? But eh, as it went further on, you know I thought, 'no, I just really feel as if that's me back to feeling what I should be like.'" (Anne, pg 4, lines 132 – 145).

Anne's reference to *'the depressive one'* is a powerful illustration of her sense that depression creates a different identity to the person she identifies with being. This phrase also conveys a sense that she is distancing herself from this 'depressed identity' now she sees herself as not depressed.

When discussing her concerns about ECT, it became clear that Mary also believed she was not herself when she was depressed:

Mary: "Now, I could say to someone, 'oh have it done, it's not going to change you'. But at the time, you don't know that."

Interviewer: "and that was one of the worries you had before? Before getting it [ECT]?"

Mary: “Yeah. And when I think about it, my personality had been taken away anyway, I wasn’t myself.”

Interviewer: “Because of the depression?”

Mary: “Because of the depression.” (Mary, pg 8, lines 244 – 249)

In this extract, Mary not only states she ‘*wasn’t herself*’ when depressed, but goes as far as to say her entire personality was absent or removed in some way. This is a powerful expression of how her sense of who she was changed when she became depressed. There is a sense of absence, emptiness and loss, and a reluctance or inability to relate to the person she was when she was depressed.

‘It must have been some chemical alteration’

None of the participants appeared to view their ‘depressed selves’ as part of them, instead focusing on depression as an external entity, as something separate from ‘them as a person’. When discussing the circumstances that led to her ECT, Judith describes her initial experiences of depression:

“I mean, I couldn’t understand it because I have a lot of interests, and I’m never bored in truth, but this low feeling, I couldn’t get rid of it and began to think ‘this is awful’.” (Judith, pg 1, lines 34 – 36)

The phrase ‘*I couldn’t get rid of it*’ conveys a sense that Judith views depression as an external entity that has somehow attached itself to her, that she is unable to remove. Additionally, this quote alludes to her feeling of powerlessness to recover from depression,

indicating that she could not see any way to ‘get rid’ of this low feeling despite the impact it was having on her life. This sense that depression is something external and uncontrollable is echoed by Anne, when she states depression ‘*cropped up*’ on her:

“He [husband] just straight away said, when it cropped up, that he was quite happy because the last time [she had ECT] he didn’t think it was for me, but since then, he says ‘when I saw how she got on before’ he was quite happy, mmm - hmm.” (Anne, pg 2, lines 66-68).

This quote conveys that Anne experienced the onset of depression as unexpected and surprising, and something that did not have an obvious cause or trigger. In addition, all of the participants described depression as an ‘it’ and seemed to conceptualise their difficulties as something separate from themselves and something inconsistent with their self-concept. Again, when discussing how she came to have ECT, the following quote from Maggie reveals her belief that to be depressed is not in her nature, implying that depression is something that fundamentally goes against who she is as a person:

“Well, I’m not really normally depressed. My own nature in the past has been more sort of, half full rather than half empty.” (Maggie, pg 2, lines 47 – 48)

While discussing their experiences of depression and the context in which they came to receive ECT, it was clear that participants were conceptualising depression within the context of a medical model, attributing its cause to biological mechanisms:

“I can’t now imagine what it felt like to be so low, I just can’t. And I can’t even sort of, reason and think ‘how on earth did you get like that?’ I don’t know, it must have been some chemical alteration.” (Judith, pg 5, lines 195 – 197)

Here, it seems as though the experience of depression is so removed from how Judith sees herself now that she describes being unable to fathom how she became so low. In the absence of being able to understand this, it seems that she develops a lay concept that the source of her depression must be due to some uncontrollable biological change and is in no way related to her or her concept of herself. When asked about her recovery from depression, Mary attributed ECT's success to a change within the chemistry of her brain, again indicating her belief that depression has a chemical origin:

"...nobody actually explained what it actually does to your brain, does it just give it a wee jolt and get it from being really low and up again? Or is it the serotonin levels that get made higher and you know, that sort of thing". (Mary, pg 5, lines 141 – 143)

Theme 2: Power and control

Every participant raised the issue of power and control in relation to their experience of ECT. There were two sub-themes which formed this superordinate theme: *'the decision was not really mine'* and *'what exactly are these electrodes doing to me?'* In general, most participants felt the decision to have ECT was not made by them and that they had not received appropriate information regarding the treatment and possible side effects. One participant, Judith, deviated from the other participants as she appeared to retain a sense of control and felt involved in the decision to undergo ECT. Extracts from her account are often used to represent important divergent perspectives within this theme.

The decision was not really mine

The first sub-theme within this superordinate theme focuses on the placement of power within the context of receiving ECT. This includes the perception that others held the power

and control over the decision for participants to undergo ECT, and that ultimately, others 'knew best'. When asked about the circumstances leading to ECT, Mary discusses her perception of the decision making process:

Mary: "You know, I was sort of saying 'I don't really want this procedure, I don't need it', and they were saying, 'no I really think you should have it', and I was sort of thinking 'well I've got to do what they say, but I don't really want to do it', but now I just see it as something... as part of the treatment."

Interviewer: "So the decision to go ahead with the ECT was..."

Mary: "was not really mine." (Mary, pg 5, lines 155 – 160)

In this passage, it can clearly be seen that Mary believes she doesn't need or want ECT, which is in direct contrast to the views of the health professionals involved in her care. Her use of '*sort of*' on two occasions within this extract conveys a sense of uncertainty and hesitancy in her opinion about what is best for her, alluding to the belief that 'others' (in this case health professionals) knew what was best for her. This extract also conveys a sense of coercion and passivity, illustrated by the phrase '*well I've got to do what they say, but I don't really want to do it*'. Mary seems to feel she does not have a choice and must go along with the decision that has been made, despite her own reservations about ECT. Mary's statement that the decision to have ECT was not really hers conveys the idea that ultimately others hold the power to decide for her and that her opinion was not considered. This idea that 'others know best' is elaborated in the following extract from Maggie when she talks about her initial discussions with her doctor about ECT:

“Uh... Well when I saw [Doctor] I was saying ‘I don’t really want this’, and he said, ‘but you have to have it’, and I wasn’t really happy about it, but I went, ‘cos I thought, ‘well he knows, he’s a man who knows what he’s talking about’ ”. (Maggie, pg 5, lines 174 – 176)

Again, it can be seen that although Maggie is clearly stating she didn’t want ECT and felt unhappy about the prospect of having it, she proceeded to give consent and undergo treatment. She justifies this action with the statement *‘he’s a man who knows what he’s talking about’* clearly illustrating that she viewed the doctor as someone who was knowledgeable regarding what was best for her. The fact she proceeded with the treatment implies that the doctor’s opinion and knowledge about that was best, ‘trump’ her own opinions and knowledge.

Looking at other participants experiences, ‘others’ are not always health professionals. In Anne’s case, on both occasions her husband ultimately made the decision regarding her ECT treatment:

“Now I don’t know how long it took to, eh, to have the first treatment, like from being admitted, I forget that part, ‘cos as I say, I don’t remember much at all about the first two weeks. I didn’t even realise I’d had the treatment, you know, but as I said, [husband] consented straight away at that point.” (Anne, pg 3, lines 108 – 111)

This extract illustrates Anne’s confusion around the events that lead to the decision for her to have ECT and the procedure itself. The fact that she didn’t realise she was having ECT until two weeks into the treatment engenders a sense of passivity and lack of control. This passivity is further evidenced when Anne discusses the consent process in more detail:

Interviewer: “And you don’t remember people asking you if it was ok to go ahead with ECT ‘cos you were really down at that point?”

Anne: “Really really down, uh-huh I suppose I was aware of it happening, but just went along, kind of, with it.” (Anne, pg 2, lines 40 – 43).

The fact that someone else (her husband) ultimately consented and decided what was best for her echoes other participants experiences in that they had limited power and control to in the decision to have ECT.

As already mentioned, Judith’s experience differed compared to the other participants as she felt involved in the decision making process and appeared to retain a sense of control regarding her treatment:

“I wanted a different kind of... I didn’t want to feel my life had ended and there was nothing, and I knew somewhere out there was a better life, and so when [Doctor] suggested ECT and more or less explained it, I thought ‘well, I will go ahead’, and I think I started the first ECT in April, twice a week, and the last one was at the end of May, and I had nine ECT sessions all together here, and I began to feel better from the second or third one.” (Judith, pg 2, lines 53 – 57)

This statement conveys a sense of collaborative involvement in the decision to have ECT. The use of the word ‘*suggested*’ clearly implies that Judith perceives ECT to have been put forward as an option for her consideration rather than forced upon her by others. The phrase ‘*well, I will go ahead*’ is also a clear statement that it is her making the decision to undergo ECT. However, this extract begins with the statement ‘*I didn’t want to feel my life had ended and there was nothing*’ which creates a powerful sense of sadness and illustrates her

desperation for things to change. Whether a decision made within this context can truly be considered a free decision is questionable. This is expanded on further in the following extract:

Interviewer: "...and do you feel it was your decision to have ECT?

Judith: "it was my decision because I agreed to the suggestion, if that is the right thing, because I hadn't suggested it and it was the doctor who suggested it" (Judith, pg 7, lines 255 – 257)

Although Judith states that having ECT was her decision, she then qualifies this by stating she agreed to a suggestion made by the doctor. Taking this together with her previous quote, there is sense that she felt she had reached a point where she would consider any course of treatment in order to resolve her symptoms of depression. Nonetheless, she felt involved in the decision and felt she retained power and control in relation to the decision to undergo ECT.

What exactly are these electrodes doing to me?

Participants had different experiences in relation to how informed they felt regarding ECT. One participant felt uninformed, one participant felt fully informed and two did not recollect the period of time when the decision to undergo ECT was being made. When asked about her interactions with medical staff before her procedure, Mary reported that she felt there was a lack of information provided to her about the effects of ECT:

“It didn’t physical affect me at all. Mentally, I don’t really know what it did. Nobody really explained what, I don’t even know if they know actually, what it does to the brain. Do they? Do they understand what? (Mary, pg 6, lines 185 – 187)

In this extract, Mary seems to initially believe that information was being withheld from her in relation to the effects of ECT, but as she is talking, she begins to question whether ‘they’ (health professionals) actually have the information themselves. This is in contrast to her opinions discussed previously where she believed that others were more knowledgeable about what treatment was best for her. When asked what she thought may have been more beneficial for her, Mary states that the information provided could have been in a more helpful format:

“I think yes, perhaps a little more information before, maybe, and someone speaking to you afterwards, give you a bit more one to one, rather than just giving you a book for you to read, because the state that you’re in, you’re not taking that in. Now I would take it in, but then it was just “I don’t want this” and you know, you’re given this big book about your rights and all these sort of things.” (Mary, pg 7, lines 226 – 230)

From this extract it can be seen that Mary feels that more information could have been provided before and after treatment in a one to one, oral format. It seems that by giving her the information in written format, Mary felt both dismissed and overwhelmed. This sense of being dismissed is apparent in her use of the word ‘just’ in reference to the information she was given to read and in her implication that nobody took the time to discuss her treatment one to one with her. A sense of feeling overwhelmed is conveyed in her use of the phrase ‘big book’. In reality a leaflet is provided with information on consent and patient’s rights, however, it is clear that this felt like an overwhelming amount of information for her to digest, particularly when she was feeling low in mood and lacking in concentration.

Maggie was also provided with written information about ECT, and like Mary, it appears as though she felt this information was not particularly helpful, illustrated by her quote below:

“Yeah, that [how ECT works to relieve depression] wasn’t really explained to me. I would have preferred if someone, maybe if I did speak to someone, if someone did speak to me and say exactly what these electrodes were doing to me” (Maggie, pg 6, lines 190 – 192)

Here, it is clear that Maggie wanted information relevant to how the treatment might affect her, and the mechanism of action of ECT rather than on her rights indicated by the phrase ‘*if someone did speak to me and say exactly what these electrodes were doing to me.*’ In this passage she repeats ‘*someone*’ three times, again emphasising her desire to have a one to one discussion with a person rather than written information.

Judith’s experience differs from Mary’s experience. When asked about her feelings when ECT was initially suggested, it is clear that Judith felt she was able to undertake research into ECT herself:

Interviewer: “How did you feel when it [ECT] was initially suggested?”

Judith: “ I wasn’t sure, because I had read (I’m a reader) and I’d read such awful things, but I also knew that it wasn’t the way it used to be, and it was totally different and when I spoke to [Doctor] and other people, like staff in the hospital, I realised it wasn’t such a horrendous... I didn’t like the idea of intrusion into your brain, but on the other hand, I thought “something’s got to be done here to make me feel more like me” because there is a me somewhere in there and so, I thought, right we’ll go ahead, so we did. And I didn’t have any regrets.”
(Judith, pg 2, lines 58 – 64)

It is clear that Judith's reading and research into ECT had left her feeling conflicted, but the opportunity to speak with health professionals about this appears to have allowed her to develop her opinion. This is further evidenced by Judith's use of 'we' rather than 'I', which implies a sense of collaboration with health professionals. She goes on to weigh up both sides and comes to the conclusion to go ahead with the treatment. This process appears to have increased her sense of involvement in the decision to undergo ECT, which is consistent with her comments in sub-theme two, where she retains a sense of control and decision-making in relation to her treatment.

Theme 3: Changing beliefs about ECT

The third superordinate theme emerging from the interviews concerned participants changing beliefs about ECT throughout the course of their experience, shifting from an initial reluctance and fear to an apparent acceptance, where they came to regard it as a necessary medical procedure. Within this theme, four sub-themes were identified: *'I would do anything just to be back to normal'*, *'Oh yes, there was a fear before'*, *'And you did it, and that was it'* and *'I think it possibly gave me a wee jolt'*.

I would do anything just to be back to normal

All participants conveyed a sense of desperation or determination to recover from depression. When asked about her decision to have ECT, the following quote from Judith illustrates this sense of determination:

"The over-riding thing in my head was to get better. Whatever I had to do to get better was going to be done". (Judith, pg 7, line 262)

This was echoed by Mary when asked whether she would have ECT again:

“Whether it [the ECT] did any good or not, I don’t really know, but if I got really severely depressed [again] yes, I would do anything just to be back to normal”. (Mary, pg 7, lines 222-224)

The phrases ‘*whatever I had to do to get better was going to be done*’ from Judith and ‘*I would do anything just to be back to normal*’ from Mary convey a real sense of desperation and commitment to do whatever was necessary to treat their depression.

As time passed and other treatments were not relieving their symptoms, participants’ perspectives appeared to shift as they began to believe there was no other alternative to treat their depression. The following quote from Judith conveys this shift and the eventual conclusion that her only remaining option was ECT:

“Well, I was prepared to do anything to feel better because life was so awful, so I was in the ward and saw [Doctor] and got more treatment, more antidepressants, different ones but they didn’t seem to help. And come the end of April last year, I saw [Doctor] and he said, he suggested ECT, and I thought, ‘well things aren’t any better’.” (Judith, pg 1, lines 45 – 48)

This extract from Judith’s interview clearly illustrates the timeline of her experience and how her perceptions change over time. The phrase ‘*well things aren’t any better*’ suggests a sense of defeat – that other options that were more acceptable to her had been tried but had not improved her symptoms, and hints at a realisation that she will have to consider other options that she may not have considered at the beginning of her experience of depression.

This is echoed by Maggie's experience. When discussing the circumstances leading to ECT, Maggie revealed that before ECT was considered, she had been treated with several different antidepressants which did not reduce her symptoms of depression. This seems to have led her to believe that her only alternative was ECT:

"I didn't really fear it [ECT] too much, because I just thought 'what's the alternative here?'"
(Maggie, pg 3, lines 109 – 110)

In addition to the feeling of desperation to get better, there also appeared to be a sense of reluctance among participants to undergo ECT. When discussing the decision making process happening before undergoing ECT Mary conveys this reluctance:

"Yes, it's just like having something wrong with you just the doctor saying to you, 'but you've got to have this treatment,' so you have the treatment. It's scary, a bit scary, sort of thing, do you really want something messing about with your brain, that's the scary thing, but I'm quite ok so it couldn't have done anything! [Laughs]" (Mary, pg 7, lines 217 – 220)

While other participants expressed a reluctance to undergo ECT when it was suggested, Anne did not have the capacity to consider ECT due to the severity of her depression. When asked about this in more detail, Anne reflects that her husband *'wasn't happy'* for her to undergo ECT, conveying a sense that he also experienced this reluctance. The phrase *'it'll have to be that course we go down'* also alludes to him feeling there were no alternatives, and that ECT was the only option:

"The time before that, eh, I think that was 2007 and, eh, that was when I first had it, and [husband] wasn't happy for me to have it because I wasn't capable then of answering then. I just wasn't conscious of making up decisions for myself or whatever, and he wasn't happy

about me having it, but later on, decided yes, it'll have to be that course we go down.” (Anne, pg 1, lines 9 – 13)

Once Anne realises that she is receiving ECT again, she shares her husband’s reluctance and the view that there was no alternative to treat her depression. Her statement that she felt ‘*sad at times*’ and her question, ‘*was this the only way out?*’ illustrate this:

Interviewer: “and how did you feel when you started to realise you were having ECT again?”

Anne: “Umm, I felt, oh dear, a wee bit sad at times that it had happened again and eh, ‘was this the only way out?’” (Anne, pg 4, lines 114 – 117)

Oh yes, there was a fear before

All participants expressed worry or concern about the effects of ECT before undergoing treatment with the exception of Anne, whose husband consented for her to receive ECT due to the severity of her depression. As the following excerpt shows, when Anne realises she is having ECT, two sessions in, she describes a lack of worry or concern about it:

Interviewer: “And you don’t remember people asking you if it was ok to go ahead with ECT ‘cos you were really down at that point?”

Anne: “Really, really down, uh-huh. I suppose I was aware of it happening, but just went along kind of, with it”.

Interviewer: “Do you remember feeling any worry or concern about having ECT?”

Anne: “No, funnily enough I didn’t seem to, I just remember trying to think ‘if this is going to help, right ok’.” (Anne, pg 2, lines 40 – 47)

Although she denies being worried about having ECT, she acknowledges that this may be normal or expected with the phrase *‘funnily enough’*. Additionally, she said *‘trying to think’* which suggests that her lack of concern was not her initial, or natural reaction to the realisation she was undergoing ECT. This phrase conveys a sense that she was trying to convince herself that ECT was going to be beneficial rather than a genuine indifference.

When asked what they thought about ECT prior to the procedure, all the other participants described the experience of fear or worry, illustrated by Maggie’s quote:

“Yes I was worried about having it, wondering how it would affect me and would it affect me long term? And that sort of thing, you know, it’s something you hear about that it used to be in the olden days, that they put electrodes on your head and you’re thinking ‘I don’t want that!’ you know, but it was nothing like that.” (Maggie, pg 3, lines 153 – 157)

More specifically, these fears included detrimental effects on memory functioning, intelligence, alteration of personality, and a dislike of ‘intrusion’ into the brain. For example, Mary was concerned about the effect ECT may have on memory functioning:

“I think possibly at the time I didn’t need to have it, I didn’t want to have it, I didn’t want to, you know, I thought is it going to affect my brain, is it going to make me not remember things or stuff like that. But that didn’t really happen at all, it was absolutely ok.” (Mary, pg 2, lines 63 – 65)

Here, Mary's reluctance to have ECT is clear and she qualifies this by sharing her concerns that it would damage her memory. Judith also described worry in relation to a change in her memory, but added that she was also concerned that ECT would alter her intelligence or ability to regulate her emotions:

"Well, I wasn't quite sure how... I always considered myself to have a good intellectual brain and good emotional control, and I kind of wondered whether ECT would effect that, but I had also read that it affects your memory and, and I've always had a really good memory for detail, almost pictorial memory. And I worried about whether that would affect my memory, but it hasn't, truly." (Judith, pg 3, lines 115 – 118)

In addition to concerns about memory and cognitive functioning, Mary expressed concerns that ECT would change who she was:

Mary: "Now I could say to someone, 'oh have it done, it's not going to change you'. But at the time, you don't know that."

Interviewer: "There's a worry about the consequences?"

Mary: "That you're not going to be the same person, or you're gonna be a zombie, it's gonna take away your personality and stuff like that." (Mary, pg 7, lines 241 – 245)

It can be seen from this quote that Mary is concerned that ECT would somehow change or remove something central to her sense of who she is. It is clear she is concerned about losing her personality, and the use of the word 'zombie' conveys a powerful image of someone who is lifeless, apathetic, and unresponsive to their surroundings.

These extracts detailing concerns about the detrimental effects of ECT on memory functioning, intelligence and personality all illustrate a lay model or understanding of the notion of the self and psychological functioning. All participants were concerned that ECT would somehow change something fundamental to their sense of identity. Memory, intelligence and personality are difficult to quantify, but there is a clear sense that participants feared alterations to any of these would have a lasting impact on who they were.

And you did it, and that was it

The third sub-theme identified focuses on how participants perceived ECT after having the treatment. In contrast to participant's initial concerns that ECT was a 'last resort' and a feeling of fear regarding the procedure, it seems that some participants came to view ECT as a necessary procedure like any other medical treatment. When asked how she felt several months after the procedure, it was clear that Maggie's views had changed:

Maggie: "at the time I thought, 'oh my god, I must be really bad, I need something like this'. Now, it doesn't bother me at all, I can talk to people about it. It was an experience I went through that I needed to have to get better, just like a physical thing you needed to have something done.

Interviewer: "ok. And so it sounds as though you view ECT as a necessary medical procedure?"

Maggie: "Yes, yes. Just like taking medication." (Maggie, pg 4, lines 108 – 112)

It can be seen from this excerpt that Maggie initially perceived needing ECT to mean she was '*really bad*', however, as she progresses through treatment and into recovery, she

reflects on this and draws parallels between receiving ECT and undergoing a treatment for a physical health condition. This statement appears to normalise the procedure and illustrates a change in her view of ECT, that it is a necessary treatment for depression like treatment for any health problem.

Mary develops this idea further when asked about her current perceptions of ECT, by likening it to being on medication:

“It’s like being on the medication; I don’t mind being on the medication if that keeps me right, that’s absolutely fine”. (Mary, pg 4, lines 105 – 106)

This quote indicates that to Mary, a treatment is a treatment and there is nothing particularly different or special about ECT. She acknowledges that if something works for her, then she is willing to accept that that’s what she needs to do. Anne’s view appears to be in line with Mary’s, illustrated in the following quote:

Interviewer: “and at that stage [after ECT], what did you think of the ECT?”

Anne: “I seemed to be quite happy with it, uh-huh, there was no problems at all with it, it just seemed to be something that helped me and you did it and that was it.” (Anne, pg 3, lines 86 – 88)

Anne’s phrase ‘*it just seemed to be something that helped me*’ indicates that she views ECT as a necessary procedure, and conveys a sense of acceptance of the treatment. However, the end of her sentence ‘*and you did it and that was it*’ suggests a sense of finality and hints that she felt there was no choice or no way to resist this course of action.

I think it possibly gave me a wee jolt

When asked about their recovery from depression, all participants expressed the belief that ECT improved their depressive symptoms, however, participants varied in the extent with which they believed it was responsible for their overall recovery from depression.

Mary: “Before [the ECT], I was really quite ill. Afterwards, I gradually started getting better. Whether it was that, or whether I was just going to get better or not I really don’t know.”

Interviewer: “Ok. So, there’s part of you that thinks its maybe due to the ECT and part of you thinks you would have got better anyway?”

Mary: “Yeah, I think so. I think it was just time.” (Mary, pg 2, lines 49 – 53)

It can be seen here that although Mary states she started to improve following treatment with ECT, she remains rather ambivalent about whether it actually contributed to her recovery. By the end of the excerpt she actually appears to attribute her recovery from depression as simply due to the passing of time. She goes on to say that subsequent cognitive behavioural therapy and medication also contributed to her recovery.

This sense of ambivalence about the efficacy of ECT is seen again in another excerpt from Mary, where she is discussing what improved her symptoms:

“I was fighting against it [ECT], but I think it was the right thing to do. I think it possibly gave me a wee jolt, and got the depression sort of, got it a wee bit better than it was.” (Mary, pg 6, lines 228 – 229)

Again, although on the surface Mary appears to be acknowledging that ECT improved her symptoms, her use of the words '*possibly*', '*wee*' and '*sort of*' convey a sense of uncertainty or hesitancy at attributing her improvement to ECT. Alternatively, the use of this language may indicate a minimising of the contribution made by ECT - that although she is acknowledging that ECT helped, she is not convinced that it had a major effect on her recovery.

Anne, Maggie and Judith are less hesitant about attributing their improvement to ECT. Maggie states that she started to feel better after her first treatment:

Interviewer: "And what did you think when you woke up from your anaesthetic?"

Maggie: "Oh, I was really settled".

Interviewer: "So you felt different immediately?"

Maggie: "Yes, I felt different, I didn't have that nervousness. That was away". (Maggie, pg 3, lines 64 – 67)

Judith reports starting to feel better after two or three sessions:

"I started the first ECT in April, twice a week, and the last one was at the end of May, and I had 9 ECT sessions all together here, and I began to feel better from the second or third one." (Judith, pg 2, lines 55 – 57)

When asked how she felt after starting treatment, Anne also describes starting to feel better quickly after completing her initial sessions of ECT:

“I just remember beginning to feel just so much better, uh-huh, and, eh, being able to think better, and really felt I’d got on fine and I was discharged, and taken care of, you know, just after that, and eventually just everything wrapped up kind of thing.” (Anne, pg 2, lines 37 – 39)

Here Anne reports feeling much better after treatment and describes being able to think more clearly. However, she is still unsure whether this was totally due to ECT rather than a combination of medication and ECT:

Interviewer: “So how was the experience [of ECT] this time?”

Anne: “It seemed to... For me, I think it lifted quicker, even quicker this time. Whether it was a combination of the two, [the medication and the ECT] it, eh, it could be that.” (Anne, pg 2, lines 60 – 62)

Although initially stating she felt better after two or three sessions, Judith reports questioning her improvement after treatment, attributing this to a difficulty having a truly objective sense of herself:

“I don’t think you have insight into... well you have insight into how you feel, that’s true, but insight into how normal you are maybe? I don’t know, it’s hard to say for yourself. Although I felt a lot better, there was a doubt” (Judith, pg 4, lines 139 – 141)

As she elaborated on this however, she cited several examples of others noticing her improvement which seems to have reassured her that she was recovering:

“My [family member], who lives in [place name], and she’s retired, and she’s involved in a lot of stuff to do with people with learning difficulties as a volunteer, she said that she saw a big difference after the ECT, I mean immediately after the ECT” (Judith, pg 4, lines 134 – 136)

In addition to participant’s recognition that ECT had, on some level, improved their depressive symptoms, all of the participants conveyed a sense that having ECT had somehow restored them to their previous, ‘non-depressed’ or ‘real’ selves. The following quote from Anne illustrates this viewpoint:

“You’re not thinking a great deal about yourself [when you’re depressed], you know, your confidence and everything, and you wonder what, what’s the real me, kind of thing. That’s the bit and I got, I was wee bit kind of worried that the better part of me... was that a different kind of person? Or was I more like the depressive one? But eh, as it went further on, you know I thought, ‘no, I just really feel as if that’s me back to feeling what I should be like’ ”.
(Anne, pg 4, lines 141 – 145)

Although she initially questions whether ‘the real’ her is more like her depressed identity, as time passes she comes to the conclusion that the way she feels after treatment is the self-concept she identifies with and acknowledges that she is feeling the way she should be.

When discussing how she felt after her course of ECT, Maggie also revealed that she felt as though her ‘true’ self had returned:

Maggie: “It [the depression] had gone, aye”

Interviewer: “That must have been nice”.

Maggie: “Oh aye, oh it was nice all right. It was just great, just to be yourself again.” (Maggie, pg 3, lines 77 – 79)

Judith also discusses her sense of self after treatment, reflecting that she is still herself, and that she believes others would agree with this.

Interviewer: “So, do you think ECT has affected you in any way?”

Judith: “No, I wouldn’t say so. Well, I don’t think so, and people, most people, anyone I’ve spoken to, just accepts that I’m me, as I’ve always been me. I don’t think I’m any different now.”(Judith, pg 3, lines 122 – 124)

Follow-up sessions

In addition to the three superordinate themes identified, participants’ experiences of attending follow-up sessions were considered. It was not felt that this warranted the development of additional superordinate themes as only two participants (Anne and Judith) had the opportunity to attend sessions. However, it was felt that the issues raised were of interest so they are reported below. Both participants attended two sessions. When asked about their opinions of these sessions, initially, both Anne and Judith reported that they felt unnecessary, as can be seen in Judith’s quote below:

Interviewer: “And what did you feel about those [follow up] sessions? What were your thoughts about them?”

Judith: “Unnecessary! That sounds a bit arrogant, but I just thought what am I here for? I don’t see why I’m here ‘cos to me they [the tests] were so simple.” (Judith, pg 7, lines 278 – 280)

However, as they reflected on them, both agreed that they served to provide reassurance, and Anne added that she felt they gave her a sense of normalisation and closure. A sense of reassurance seemed to come from the knowledge that they were performing well on the tests, which provided reassurance that their cognitive functioning had not been impaired by ECT:

Interviewer: “And how did you feel that [the follow up sessions] was? What’s your thoughts about that?”

Anne: “I felt that just the knowledge that I was able to do that, and do it not too badly and what not, again that felt good.”

Interviewer: “So the wee tests you were doing, ‘cos you were doing ok in them, that felt quite reassuring?”

Anne: “Yes. I just felt that way.” (Anne, pg 9, lines 310 – 316)

In addition to this, Anne felt that having these sessions gave her a sense that she was not alone in the experience, and that there were other people in a similar position:

Interviewer: “So what do you think those [follow up] sessions gave you, if anything?”

*Anne: “Just to realise that there’s other folks, you know, in the same position at times”
(Anne, pg 9, lines 319 – 320)*

The fact that these sessions existed and that other people attended them seemed to give Anne a sense that she was not the only person to go through this experience, and reduced her sense of stigma or shame. Anne also reported she obtained a sense of achievement and closure from these meetings:

Interviewer: “Do you think there were any other benefits to those [follow up] sessions”

Anne: “Uh-huh, it... maybe just another step in the right direction kind of thing, like, ‘I’ve tackled that’, and ‘I’ve done that’.” (Anne, pg 9, lines 328 – 331)

From the phrases ‘*I’ve tackled that*’ and ‘*I’ve done that*’ it is clear that Anne attributes her progress to herself, and that she feels a sense of achievement at overcoming depression. Anne’s use of the phrase ‘*step in the right direction*’ conveys a sense that she views her experience as a journey, and that these meetings mark another milestone on the road to recovery for her.

DISCUSSION

The aim of this study was to explore how older adults understood and described their experiences of ECT in Scotland. Three superordinate themes emerged from the interviews that captured the participants' experiences. '*Experience of depression*' illustrates the significant impact depression had on participants' identity and the perception that depression was an external entity over which they had no control. The second theme '*Power and control*' relates to most participants' perception that the decision to have ECT was not theirs, and the belief that they were not fully informed about the treatment and its possible side effects before undergoing ECT. The final theme, '*Changing beliefs about ECT*' captures how participants' perceptions of ECT shifted from an initial reluctance and fear of ECT to an apparent acceptance, where they came to regard it as a necessary medical procedure that improved their depression. In addition, by exploring participants' views of post ECT follow up sessions it was found that although participants' initial impressions were that they were unnecessary, upon reflection, they agreed they served to provide reassurance, normalisation and closure.

As noted in the introduction, most research to date has focused on investigating aspects of ECT such as efficacy, dosage, mode of administration, cognitive effects and mechanism of action with comparatively little research exploring the complexities of how patients make sense of their experience and the meaning it holds for them (Chakrabarti et al., 2010).

Although limited in number, qualitative studies tend to report common themes including: feelings of coercion and powerlessness during the consent process (Fisher et al., 2011; Johnstone, 1999; Orr & O'Connor, 2005; Smith et al., 2009); a lack of information regarding the risks and procedure of ECT (Fisher et al., 2011; van Daalen-Smith, 2011; Smith et al., 2009; Johnstone, 1999); and a fear of ECT (Johnstone, 1999; Koopowitz et al., 2003).

Aspects of all three superordinate themes emerging in the current study have some similarities to themes identified in the literature. Aspects of the first superordinate theme (*'Experience of depression'*) were consistent with Orr and O'Connor's (2005) findings among older adults, particularly those centering on the view that depression is a powerful, uncontrollable external entity. However, in addition to these findings, the current study identified a belief that depression had a significant impact on identity, with participants describing two distinct selves. The second superordinate theme (*'Power and control'*) is particularly consistent with findings from the available literature regarding experiences of ECT, identifying feelings of coercion and powerlessness during the consent process (Fisher et al., 2011; Johnstone, 1999; Orr & O'Connor, 2005; Smith et al., 2009) and a perceived lack of information regarding the risks and procedure of ECT. Aspects of the third superordinate theme (*'Changing beliefs about ECT'*) also relate to the existing literature, specifically the acknowledgment that there was a fear of ECT. However, again diverging from studies already published, the current study found that these beliefs changed throughout the process of treatment, and ECT came to be viewed as 'just another treatment'. In line with findings from Chakrabarti et al., (2010), despite these issues, participants in this study viewed ECT as helpful in relieving their symptoms, although interestingly, a significant amount of ambivalence remained regarding the extent to which ECT was responsible for their recovery from depression.

Experience of depression: the first theme explored the participants' perceptions of the wider experience of depression. All participants viewed depression as a powerful external entity over which they had no control. They also experienced the onset of depression as unexpected and surprising, and were unable to identify a cause or trigger. These experiences of depression may relate to the fact that ECT is more likely to be indicated for those with severe, treatment resistant depression, and this may be more likely to be experienced as powerful and overwhelming. The perception of depression as an external

force with an unknown cause is in line with the findings from Orr and O'Connor's (2005) qualitative study investigating older women's experiences of ECT. While this lack of control and perceived powerlessness initially may appear to be frightening, Orr and O'Connor (2005) hypothesised that this externalisation and sense of disconnection from the experience of depression may actually be protective, allowing participants to separate the illness from themselves and protect their sense of self. This externalisation of difficulties is found in many psychotherapeutic approaches, for example, narrative therapists identify that a key aim of therapy is to help the patient come to understand that they are not inextricably linked to their difficulties and that their identity is not defined by them (White, 2007). This separation of 'you' and 'the depression' is thought to enable positive change as the illness can be conceptualised as something not related to the core concept of the self, and therefore no threat to identity. This was apparent for the participants' in this study when they referred to the creation of two different selves – a 'depressed self' and a 'real self'.

Overall, participants' sense of identity in the current study appeared to remain unaffected throughout their experience of ECT, in contrast to the findings of other studies where participants experience a loss of part of their sense of self (Johnstone, 1999; Hequet, 2008). In addition to conceptualising their experience of depression as an external entity, several other factors were identified that add further support to the hypothesis that externalisation may be protective for self-concept or identity. Firstly, some participants attributed the cause of their depression to biological mechanisms or a chemical imbalance within the brain. In this conceptualisation, the cause of depression is something outwith their control or responsibility, and unrelated to their concept of who they are. Additionally, the lack of impact on identity for participants' in the current study compared to previous studies may be due to differences in perceived loss of memory. Participants in the current study reported memory loss for events happening around the time of their treatment, but did not perceive this to be significant and denied any lasting damage to their memory. In contrast, participants in the

Johnstone (1999) and Hequet (2008) studies report memory loss, particularly autobiographical memory loss, as a significant concern. Given the close link between autobiographical memory and the construction of the self and identity (Conway, 2005), it may be that participants in the current study did not experience an impact on their sense of identity because they perceived there to be no significant impact on their memory.

Power and control: the second theme examines issues of power and control raised by the experience of ECT. All participants except one (Judith) perceived that others held the power and control over the decision for them to undergo ECT. Even though Judith retained a sense of involvement in the decision to have ECT, she acknowledged that by the time it was suggested, by her doctor, she had reached a point where she felt there was no other treatment alternative. Under these circumstances it is questionable whether this can truly be regarded as a free choice; however she believes that she ultimately had the final decision regarding her treatment. This appears to have allowed her to retain a feeling of power and control. This was not the case for the other participants. In all their accounts there is a sense of coercion and passivity, conveying the idea that ‘others’ held the power to decide whether they should have ECT. In two accounts this ‘other’ was a medical professional, usually their psychiatrist, but in Anne account it was her husband. This sense of perceived coercion has been repeatedly reported in the literature investigating younger adults’ experiences of ECT, and rates of reported coercion consistently range from 25% to 33% across studies (Rose et al., 2005). Some authors believe patients consent to ECT despite feeling pressurised due to trust in their doctors’ opinions (Rajagopal, 2008), whereas others believe this consent is given due to feelings of powerlessness and desperation (Johnstone, 1999; Koopowitz et al., 2003). Results from the current study indicate that both these factors may be influencing this process. There was a sense that participants trusted the ‘others’ involved, believing that they had knowledge and skills that meant they were better qualified to make the decision. However, this was tempered with indications of passivity, that participants were quashing

their personal reservations and undergoing this procedure because 'others knew best'. There also seemed to be a legitimisation of the use of ECT as participants reported being so unwell they couldn't consent, perhaps implying the decision was taken out of their hands. There was a clear indication that they were desperate to overcome depression and that ECT was viewed as their 'last resort' for treatment. The older women interviewed in the Orr and O'Connor (2005) study also reported that they did not feel they could influence decisions about their care, however, interestingly, none saw this as particularly problematic.

Related to feeling involved in the decision to have ECT is whether participants felt informed about what the procedure would entail. With the exception of one participant (Judith) who felt well informed about ECT, most participants reported that they did not receive appropriate information about the treatment and its possible side effects before undergoing ECT. This is in line with findings from a review of 75 studies completed by Chakrabarti et al., (2010) which found that only a small proportion of patients across different studies were aware of the basic principles of the procedure (e.g., that it involves electricity or induces a seizure), and even fewer patients were aware of the more intricate aspects (e.g., techniques, side effects, mechanism of action etc.). Interestingly however, Tang et al. (2002) argue the extent of awareness among patients undergoing ECT is similar to that found among those undergoing other surgical procedures, so this may not be an issue specific to ECT. It is interesting to note that Judith attributes her feeling of involvement and control to her doctor and other medical staff taking the time to explain the procedure and possible side effects that reduced her anxiety and resulted in her feeling knowledgeable about what it entailed. In line with this, another participant (Mary) received information in a written format but felt it should have been provided in a one to one oral format as she struggled to comprehend the information due to her depression. There was also a sense that she felt dismissed due to her perception that medical professionals did not take the time to discuss the procedure with her. This is in line with recommendations made by SEAN (SEAN Standards, 2013), and Chakrabarti et al.,

(2010) following their review. SEAN (2013) recommend that information is given both verbally and in writing, that ECT is explained by a suitably qualified individual and that risks and benefits are explained and recorded. Additionally, it is stated that patients should be made fully aware they can withdraw consent at any time. Similarly, Chakrabarti et al., (2010) stated that all patients undergoing ECT should receive a detailed and comprehensive explanation of the treatment beforehand from the patient's own doctor, and that sufficient time is provided for patients to absorb the implications and express any fears and worries.

Changing beliefs about ECT: As participants progressed through their experience of depression and ECT, their views of the procedure appeared to shift from an initial reluctance and fear to an apparent acceptance, where they came to regard it as a necessary medical procedure that worked to improve their depression. Initially, there was a clear sense from all participants of a desperation and desire to 'get better'. As time passed, and their symptoms were not improving with other treatments, participants' appeared to view this as the severity of their depression worsening, and seem to become increasingly desperate for 'something' to be done to help them feel better. There is a sense that participants 'hit rock bottom' or reached a critical point in their illness experience where they would consider anything that may help restore their 'real selves'. Although participants' initially expressed reluctance about undergoing ECT and considered it a treatment of last resort, by the time ECT was proposed, it seems that participants feared they were so severely depressed that nothing but ECT would have worked to reduce their symptoms. This finding is consistent with those of Smith et al., (2009).

Consistent with the reluctance to have ECT, most participants reported being worried or fearful about the effects of ECT prior to receiving it. Concerns were expressed about the detrimental effects of ECT on memory functioning, intelligence and personality. This may have been due to the participants in this study all being older adults, who may be more

fearful or preoccupied with issues of memory loss or dementia due to their stage in life. However, these findings are in line with studies of younger adults (Johnstone, 1999; Koopowitz et al., 2003) who also report anticipatory fear about the procedure in addition to concerns about long-term damage, including personality change and memory. The fact that these findings are also found in studies with younger adults and not specific to studies with older adults indicates that pre-treatment concern is related to something about the procedure itself rather than something about the recipient. Results of this study extend this finding by examining in more detail what meaning these changes would have had for participants. Fear of ECT in this study did not seem to be related to the procedure itself, but to the worry that ECT would somehow change something fundamental to their sense of identity, and have a lasting impact on who they were. Lack of fear regarding the procedure may be due to changes made to service provision in Scotland as a result of the SEAN Standards (2013). These include changes to the environment and procedures involved in ECT, for example, having designated nurses with experience of ECT, nurses being known to the patient and present throughout the course of treatment, and not waiting longer than 30 minutes for treatment. These changes may serve to lessen the fear of the ECT procedure itself, however the threat to identity was clearly perceived to be threatening to all participants, particularly when considered in relation to the first theme '*Experience of depression*'. Here, participants convey the importance of becoming their 'real selves' again after depression claimed their 'real identity'. The fact that an apparent treatment for depression could result in the same outcome appears to generate significant fear for participants, and it is important to keep this in mind throughout the consent and treatment process.

Interestingly, although all participants reported post-ECT concern, none of the participants reported significant cognitive problems or autobiographical memory losses after ECT which is a common finding among studies with younger adults (Johnstone, 1999; Koopowitz et al., 2003; Rose et al., 2004; Smith et al., 2009). This may be because the particular sample in

this study did not experience any change to their cognitive function whereas other older adult samples may find this to be the case. However, it could also be a consistent finding among older adults, related to an increased expectation or acceptance of memory difficulties as part of the aging process. As only two studies have investigated older adults' experiences of ECT, it is not yet possible to make any conclusions regarding this point.

ECT was initially perceived as 'different' and somewhat threatening for participants, however this perception changed significantly over the course of participants' experiences. After treatment, most participants came to view ECT as a necessary procedure like any other medical treatment. There appears to be an acceptance of ECT as a treatment that was needed to resolve their depression, just like medication or psychotherapy. This is a finding not documented in the literature with younger adults, where previous research has found that when fear of ECT exists, it does not generally diminish even on completion of treatment (Chakrabarti et al., 2010). It may be as Orr and O'Connor (2005) propose: that participants' narratives are shaped by the medical social context due to a lack of other available ways to interpret or develop an understanding of their experiences, so they are forced to come to this conclusion. ECT is prescribed by psychiatrists, administered within a hospital medical ward, with medical staff caring for the patient, all of which may strengthen the medical narrative of the experience. Although this could be viewed negatively, it could also be argued that making sense of the experience, including the experience of depression, in this manner is actually protective, preventing participants from attributing the blame or responsibility for developing depression to themselves. This links with the first theme '*Experience of depression*' where participants conceptualised depression as an external entity with a biological, chemical cause, and may go some way to explain the apparent lack of impact of ECT on participants' sense of self in this study.

Alternatively, these differences between younger and older adults' experiences of ECT may be due to cohort differences based on maturing in a specific historical time period. This leads to the development of different skills, values, and life experiences when compared to those from other cohorts, and may alter the way in which experiences are interpreted and the meaning they hold. These cohort beliefs may influence older adults' perceptions about the role of a medical professional when compared to younger adults. They may have been socialised to automatically trust doctors and accept their opinions because generationally there is a belief 'doctors know best', whereas younger adults may be more likely to question medical opinion. Additionally, the tendency towards higher utilisation of medical services due to increased physical health conditions among older adults may impact on beliefs and attitudes surrounding medical procedures. Older adults may become more used to submitting to medical professionals, and procedures, operations and medication may be viewed as a necessary part of life and become more acceptable.

Although participants expressed a belief that ECT improved their depressive symptoms, they retained a certain ambivalence regarding the extent to which it was responsible for their overall recovery from depression. While all participants reported benefitting from ECT, believing it to have restored their 'real selves', on deeper discussion they also attributed their recovery to medication, psychotherapy and the passing of time. These conflicting and somewhat contradictory findings illustrate the importance of utilising a qualitative approach to gain further information regarding the subjective experience of ECT. Previous research has found that in general, most patients have a positive view of ECT, and for most of them the benefits of the treatment outweigh the costs (Chakrabarti, et al., 2010). However, these conclusions are mainly drawn from quantitative studies asking participants to respond to statements regarding ECT, (e.g., its safety, usefulness, relative efficacy, etc.) or complete checklists about their attitudes towards ECT which is likely to represent an overly simplistic approach, failing to address the complexity of opinions (Rose et al. 2003). When data from

qualitative studies are included, it can be seen that a significant proportion of patients also have negative views regarding ECT (Johnstone 1999; Philpot et al. 2004). The findings from the current study do not indicate a negative view of ECT, rather a positive if somewhat ambivalent opinion towards it. It may be that ECT provided a 'benchmark' or 'turning point' within participants' 'illness journey'. The ambivalence regarding ECT's efficacy shows that although participants reported finding ECT beneficial, they certainly did not attribute their whole recovery to ECT. Although ECT may not have been perceived as 'curing' participants' depression, it may have acted as a turning point, demarcating 'before ECT' and 'after ECT', giving participants a point in time where they expected to begin to recover. This corresponded to participants sense of two distinct identities, the 'depressed me' and the 'real me', and ECT seemed to come between these, marking an end to the 'depressed self' and a beginning of the 'real self'.

Follow up sessions:

In addition to the three superordinate themes identified, participants' experiences of attending follow-up sessions were considered. Initially, both Anne and Judith reported that the sessions felt unnecessary; however, as they reflected on them, both agreed that they served to provide reassurance, normalisation and closure. This seemed to be linked to the knowledge that they were performing well on the tests, which provided reassurance that their cognitive functioning had not been impaired by ECT. In addition to this, Anne felt that having these sessions gave her a sense that she was not alone in the experience, and that there were other people in a similar position which seemed to reduce her sense of stigma or shame in relation to having ECT. While these sessions were designed by services to measure cognitive functioning in line with the SEAN Standards (2013), it appears they may have additional benefits for participants, and facilitate adjustment and acceptance of the procedure. However, it is important to note that this data is derived from only two

participants, and experiences may be different for others undergoing the procedure, particularly when cognitive functioning may be affected.

Implications and recommendations

By the end of treatment, participants generally found the experience of ECT to be acceptable, and found it somewhat beneficial in reducing their symptoms of depression. It is important to consider the context of participants' treatment when interpreting the results of the study. This study was completed in Scotland, and since 2009, the Scottish ECT Accreditation Service (SEAN) has been striving to improve the standards of care in ECT. Accreditation visits are carried out on all clinics delivering ECT in Scotland, and all have made significant improvements to the provision of care when delivering ECT (Scottish ECT Accreditation Network Annual Report, 2013). This may account for the generally positive experiences regarding the actual procedure of ECT, as specialist ECT nurses now staff specific ECT suites within the health boards recruited from for this study.

Limitations

The present study is not without limitations. In accordance with the design and analysis, the sample is homogenous and is not intended to be a statistically random sample. All participants were female and it would have been interesting to explore the experience of ECT from a male perspective. While 29 patients were identified as eligible participants, based on the inclusion criteria, only four agreed to take part in the study. Several potential participants were deemed unsuitable to approach by clinicians involved in their care (psychiatrists or community psychiatric nurses) due to physical illness, development of a dementia or worsening of their depressive symptoms requiring inpatient care. Additionally, 11 participants were approached by clinicians involved in their care, but decided against taking part in the study. The main reason cited for this was wishing not to revisit the experience of ECT as it was regarded as a negative or traumatic experience. This clearly

has implications regarding the findings of the current study, as it is likely to have resulted in a sample of participants who have found the most benefit from ECT, and not consider the experiences of those who found it a more negative experience.

Rose et al. (2003) report that patient led studies report lower rates of satisfaction with ECT compared to clinician led studies, and argue that this is because clinician studies tend to take place too soon after treatment, use medical assessors in clinical settings and use brief questionnaires. The present study partially addressed these issues by introducing a 6 month minimum time period since completion of ECT, using a semi-structured interview to facilitate expression of more detailed and complex opinions of the procedure, and stressing to participants that the interviewer was not part of their medical treatment team. However, due to ethical constraints it was not possible to interview patients out-with a clinical setting, which may have influenced participants' responses. Although an IPA study does not aim to be generalisable, it would have been interesting to explore the experiences of those who found ECT to be a less positive experience in order to provide a deeper and more balanced account of the procedure. Future studies could address these issues by interviewing participants in a neutral setting, ensuring the sample comprised both male and female participants, and include those with less positive experiences. Finally, although steps were taken to increase awareness of sources of bias that may be brought to analysis, it acknowledged that the principal researcher is unable to give a completely 'objective' IPA analysis of the narrative data emerging from the interviews.

Future research

Due to the paucity of qualitative research investigating older adults' experiences of ECT, it is recommended that further research is conducted to replicate, develop or add to the themes found in this study. The experiences of participants in this study were all relatively positive in that none of them reported finding the experience particularly distressing, however, previous

qualitative literature among younger adults found that a small but significant proportion of those undergoing ECT find it a traumatic experience (Johnstone, 1999; Koopowitz et al., 2003). It would be important to evaluate older adults' experiences that have been less positive as this would reveal important information about how to improve services to prevent distressing experiences. Qualitative methods appear to be particularly suited to this type of research, and IPA in particular provides a structured approach to assist in interpreting and analysing patient experiences. In addition to qualitative studies examining patient experiences, it is important to conduct more quantitative research to clarify the cognitive impact of ECT for older adults. Although this study found limited evidence that this was a concern among older adults, reports of cognitive problems and/or autobiographical memory losses after ECT have been reported in younger populations (Johnstone, 1999; Koopowitz et al., 2003; Rose et al., 2004; Smith et al., 2009). As has been reported, the quantitative literature investigating the cognitive effects of ECT for older adults is conflicting and limited by methodological weaknesses (Tielkes et al, 2008; Gardner & O'Connor, 2008). It would be important for future quantitative studies to address these methodological limitations by discriminating between the type of ECT administered, excluding patients with dementia, assessing several cognitive domains using sensitive and reliable neuropsychological tests, and measuring depression in order to control for its effects on cognitive functioning. The inclusion of a normal control group would also enable the quality of cognitive function to be determined, irrespective of depression. If these methodological issues are taken into consideration, it may be possible to establish a clearer picture regarding the effects on cognitive functioning following ECT in older adults.

CONCLUSION

This is the first study to use IPA to explore the experiences of a group of older adults who have received ECT to treat depression. Depression was found to have a significant impact on identity and to be conceptualised as a powerful external entity. Consistent with previous qualitative literature exploring the experiences of younger and older adults who have experienced ECT, issues of power, control, coercion and fear were raised. In contrast to previous studies however, beliefs and opinions of ECT were found to shift over time, and by the end of treatment participants generally found the experience of ECT to be acceptable, and found it somewhat beneficial in reducing their symptoms of depression. The current study makes several recommendations for clinicians and healthcare providers and identifies areas for future research. These recommendations can be used to contribute to improvements already made by SEAN in the delivery of care and treatment for older adults receiving ECT.

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Chapter Three: Advanced Clinical Practice I

Reflective Critical Account

Communicating a formulation and intervention plan to staff on
an inpatient dementia ward: personal and professional
reflections

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Doctorate in Clinical Psychology (DClinPsy)***

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ABSTRACT

Introduction: Reflective practice is understood as the process of learning through, and from experience and is now recognised as a key component of training in clinical psychology.

This reflective account will consider my experience of communicating a psychological formulation and implementing an intervention with an inpatient staff team for a patient displaying distressed behaviour. Scotland's National Dementia Strategy states that non-pharmacological approaches should be explored as a first line intervention for distressed behaviour, and that staff working with these patients should be supported to develop both an understanding of the causes underlying the behaviour, and appropriate skills to manage the behaviour. The Health and Care Professionals Council also identifies that psychologists should use formulations to assist multi professional communication, understanding of patients and intervention planning. Psychologists are well placed to undertake this work, however there are a number of barriers and challenges in doing so. **Reflection:** I have used Gibbs' (1988) model of reflection to structure my account of this experience. I consider my thoughts and feelings in relation to the experience, how I made sense of the experience and how I used this information to inform future practice. **Reflective Review:** In this section I discuss how the experience of writing this reflective account has informed my understanding of how clinical skills develop over time, influenced my understanding of my practice, and how this changed the way I progressed with the case. I then reflect on the implications that the issues raised through this experience have for the profession of Clinical Psychology as a whole.

Chapter Four: Advanced Clinical Practice II

Reflective Critical Account

Developing the application of psychological skills and
knowledge: reflections of co-facilitating a carers group within a
young onset dementia service

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ABSTRACT

Introduction: Reflective practice is understood as the process of learning through, and from experience and is now recognised as a key component of training in clinical psychology.

This reflective account will consider my experience of co-facilitating a carers group for those caring for a family member with a diagnosis of young onset dementia (YOD). Scotland's National Dementia Strategy acknowledges the impact of dementia on family members who provide care and support to the person with dementia and commits to improving post diagnostic support. NES published a resource for carers based on The Newcastle model of stress and distress and the YOD team decided to use this to pilot a carers group with the aim of increasing knowledge of, and confidence managing, distressed behaviour.

Reflection: I use Gibb's (1988) model of reflection to structure my account of co-facilitating one session of this group. I consider my thoughts and feelings in relation to the experience, how I made sense of the experience and how I used this information to inform future practice. I also use Kolb's (1984) Experiential Learning Cycle to consider how my knowledge has grown across the lifespan of the group by continuously applying and reapplying knowledge gained from prior experiences. **Reflective Review:** In this section I discuss how the experience of writing this reflective account has informed my understanding of how clinical skills develop over time, influenced my understanding of my practice, and how this changed the way I hope to progress with the next carers group.

APPENDIX 1.1

Instructions for Authors Submission to Aging & Mental Health

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APPENDIX 1.2

Quality Rating Scale

(Adapted from the Clinical Trials Assessment Measure, Tarrier & Wykes 2004)

Reviewer:	
Paper:	
Date:	

Sample:

1. Is the sample a convenience sample (score 2) or a geographic cohort (score 5) or highly selective sample (score 0) (Convenience sample: e.g. clinic attendees, referred patients. Geographic cohort : all patients eligible in a particular area)	
2. Is the sample size greater than 27 participants per group (score 5) or based on adequate and described power calculations (score 5)? If no to both questions score 0.	

Score: /10

Allocation:

3. Is there true random allocation or minimisation allocation to treatment groups (if yes score 10)	
4. Is the process of randomisation described (score 3)	
5. Is the process of randomisation carried out independently from the trial research team (score 3)	

Score: /16

Assessment (of main outcome):

6. Are the assessments carried out by independent assessors and not therapists (score 10)	
7. Are standardised assessments used to measure depressive symptoms in a standard way (score 6) or idiosyncratic assessments of symptoms (score 3)	
8. Is the measure of depression a valid and reliable measure? (Score 0 if not valid/ reliable, score 3 if poor validity/reliability, score 5 if valid/reliable measure)	
9. Was there a long term follow up measurement (> 6 months after end of intervention) for depression conducted (if yes score 3)	
10. Are assessments carried out blind (masked) to treatment group allocation (score 10)	
11. Are the methods of rater blinding adequately described (score 3)	
12. Is rater blinding verified (score 3)	

Score: /40

Control groups:

13. Is there a control group? (Yes – score 5)	
14. TAU is a control group (score 6) and/or a control group that controls for non-specific effects or other established or credible treatment (score 10)	
15. Are groups similar at pre-test (or adjustments made) (score 5)	

(If no control group, score 0 for this section)

Score: /26

Analysis:

16. The analysis is appropriate to the design and type of outcome measure (score 5)	
17. The analysis includes all those participants as randomised (sometimes referred to as an intention to treat analysis) (score 6) and an adequate investigation and handling of drop outs from assessment if the attrition rate exceeds 15% (score 4)	
18. Was an effect size calculation completed? (score 3)	
19. Was there sufficient information provided for effect sizes to be calculated? (score 1)	

Score: /19

Active treatment: reminiscence or life review intervention

20. Was the treatment adequately described to allow replication? (score 3)	
21. Was a treatment protocol or manual used? (score 3)	
22. Was information provided on the training of therapists (score 3) were therapists adequately trained to deliver the intervention? (if yes score 5)	
23. Was adherence to the treatment protocol or treatment quality assessed? (score 5)	

Score: /19

Total Score	/ 130
Percentage Score	%

APPENDIX 2.1

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On-line manuscript submission: All manuscripts must be submitted on-line through the new Web site at <http://ject.edmgr.com/>. **First-time users:** Please click the Register button from the menu above and enter the requested information. On successful registration, you will be sent an e-mail indicating your user name and password. Print a copy of this information for future reference. *Note:* If you have received an e-mail from us with an assigned user ID and password, or if you are a repeat user, do not register again. Just log in. Once you have an assigned ID and password, you do not have to re-register, even if your status changes (that is, author, reviewer, or editor). **Authors:** Please click the log-in button from the menu at the top of the page and log in to the system as an Author. Submit your manuscript according to the author instructions. You will be able to track the progress of your manuscript through the system. If you experience any problems, please contact the Editorial Office: emily.senerth@wolterskluwer.com, 001 215-521-8944 FREE (p), 001-215-405-2723 (f).

Article Types

The Journal accepts for publication the following types of articles. Please contact the Editorial Office with any questions regarding submission requirements for a specific article type.

Original Study – reports of both basic and clinical research into electroconvulsive therapy and other forms of therapeutic brain stimulation for mental disorders are welcomed. Original Studies should use the following headings: Introduction, Methods, Results, and Discussion. For all studies reporting animal or human research, the Materials and Methods section must include a statement regarding review board approval and adherence to ethical standards; for human research, this includes a statement regarding informed consent. A structured abstract must be provided.

Case report – Case Reports will be considered for publication as either a regular a full “Case Report” or a briefer “Letter to the Editor”. To be considered as a full Case Report, the submission must include a truly novel case that has the potential to change thinking within the field of therapeutic brain stimulation, and the submission should include a thorough review of the existing literature and explanation of how this case advances the field. In contrast, cases that are less novel or replications of prior reports should be submitted as a letter to the editor, with no abstract, no more than 1000 words, no tables or figures, and no more than 5 references. The Editorial Board reserves the right to recommend that cases submitted as 'Case Reports' be revised as letters to the editor.

Review Article – Review articles focusing on various aspects of electroconvulsive therapy and other forms of therapeutic brain stimulation for mental disorders, historical issues of relevance to current practice, or international aspects of the practice are welcomed.

Images in Clinical ECT – Images of EEG recordings or of items of clinical interest to practitioners of electroconvulsive therapy and other forms of therapeutic brain stimulation for mental disorders may be submitted for consideration. The image or picture should tell the story; the text must not exceed 500 words. If text >500 words is required, then the article should be submitted as a case report. Articles should be submitted without an abstract.

Commentary – Commentaries may focus on timely issues of interest to the international ECT community.

Letter to the Editor – Letters should focus on articles recently published in the Journal, or may describe brief case reports (see above). In general, letters to the editor should be submitted with no abstract, no more than 1000 words, no tables or figures, and no more than 5 references. If the

authors' comments do not directly relate to a recently-published article or describe a brief case report, the paper should be submitted as a Commentary. All letters should begin with the salutation "Dear Sir."

Caution regarding the use of statistics

General approach – Presentation of results from inferential statistical testing should include sufficient information such as test statistic (t , F , X^2 , etc.) and degrees of freedom (df) accompanying the p -value to document the appropriateness of the analyses. An example of results of an independent sample t -test comparison of an outcome in two groups would be ($p < 0.001$; $t = 12.5$, $df = 50$). It is also acceptable, particularly when reporting of the test statistic and df is not straightforward (as occurs in some regression modeling situations) to simply identify the inferential procedure and relevant additional information associated with the reported p -value, e.g., ($p < 0.001$; timeXtreatment interaction, mixed effects model). All statistical procedures should be described with sufficient detail in the methods section and identified in the footnotes of tables and figures.

Repeated observations in the same subject – The nature of therapeutic brain stimulation is such that patients usually receive multiple, repeated treatment sessions over a specified period of time. Our statisticians on our editorial board have noted several common mistakes in the conduct and reporting of statistics, particularly in relation to inferential statistical tests performed on repeated observation in the same patient. Depression scores, seizure duration scores, vital signs, etc. from serial treatments within the same patient are assumed to be intercorrelated *within* that patient, and hence violate the usual assumptions of independence of observations required for most statistical tests involving between group comparisons. For example, 10 individuals each having 3 measurements of HRSD scores over time (sessions) does not result in a sample size of 30 independent HRSD scores for this group. For study designs involving repeated measures within individuals, a statistical method that takes into account the repeated measures must be used.

Small negative studies – Ideally, *before any comparative trial is initiated*, a valid power analysis is carried out and a sample size having sufficient power to detect a pre-specified clinically important effect is determined. However, occasionally studies are undertaken in which no *a priori* sample size determination was made (and only available patients were used) or the pre-determined sample size is not achieved. For either of these cases in which a negative (non-statistically significant) result is obtained for the primary outcome variable(s), a *post hoc* power analysis should be carried out. If this analysis indicates power less than 80%, the results must be presented as a small descriptive and/or pilot study (and reflected in the title of the paper) rather than a confirmatory comparative study involving inferential statistical procedures. Specifically, as a small descriptive and/or pilot study, comparative results should be presented in terms of descriptive measures such as intervention effect sizes (e.g. difference in treatment means or response proportions) accompanied by appropriate confidence intervals on these differences. In the pilot study context, feasibility measures such as study refusal and dropout proportions and estimates of variances for outcome variables are relevant outcome variables and provide useful input information in the event the small study is replicated in a larger, adequately-powered sample. When a study lacks power to detect clinical important intervention group differences, the negative study results (non-significant intervention differences) produced by the inferential statistical procedures must be interpreted as "study findings are inconclusive" or more harshly as a "failed trial." This is because the failure to detect intervention group differences for the primary outcome(s) may be due to the fact that (a) the relevant clinically important differences do *not* exist in the population to which inferences are being made or (b) the statistical test simply did not have sufficient power to detect the specified important population differences that actually

exist. To be able to conclude (a) above, we must be assured that power was adequate to have found the relevant difference if it exists in the population of inference [i.e. that (b) is not the explanation for the negative finding]. When power is known to be low, the second option prevails for negative findings. For this reason, simple descriptive measures rather than inferential statistical procedures (with their accompanying p-values) should be reported for the small negative trials published in JECT. Note that regardless of power, if statistically significant differences are found for the primary outcome(s), the study qualifies for consideration for publication as a confirmatory comparative study. For this case, negative results for secondary outcomes produced using inferential methods must be interpreted as described above.

Preparation of Manuscript

Manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review.

Title page: Include on the title page (a) complete manuscript title; (b) authors' full names, highest academic degrees, and affiliations; (c) name and address for correspondence, including fax number, telephone number, and e-mail address; (d) address for reprints if different from that of corresponding author; and (e) a conflict of interest disclosure statement (see the "Conflicts of Interest" section above) including any sources of support that require acknowledgment. This includes disclosure of funding received for the work from any of the following organizations: National Institutes of Health (NIH); Wellcome Trust; Howard Hughes Medical Institute (HHMI); and other(s). If there are no potential conflicts of interest to disclose, please include a statement to that effect.

Structured abstract and key words: Limit the abstract to 250 words. Do not cite references in the abstract. Limit the use of abbreviations and acronyms. Use the following subheads: Objectives, Methods, Results, and Conclusions. List three to five key words.

Unstructured abstract and key words: Limit the abstract to 250 words. It must be factual and comprehensive. Limit the use of abbreviations and acronyms, and avoid general statements (e.g., "the significance of the results is discussed"). List three to five key words or phrases.

Text: Organize the manuscript into four main headings: Introduction, Materials and Methods, Results, and Discussion. Define abbreviations at first mention in text and in each table and figure. If a brand name is cited, supply the manufacturer's name and address (city and state/country). Acknowledge all forms of support, including pharmaceutical and industry support, on the title page of the manuscript.

Abbreviations: For a list of standard abbreviations, consult the *Council of Biology Editors Style Guide* (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use unless it is a standard unit of measure.

Technical Parameters of ECT devices and other brain stimulation devices: Authors should routinely report the make and model of brain stimulation devices, along with the location of the manufacturer. Where relevant, stimulus waveform, stimulus intensity, electrode placement, and seizure duration should be reported. The stimulus waveform, stimulus intensity, electrode placement, and seizure duration monitoring details for ECT should follow the suggestions of "Reporting of Technical Parameters in ECT Publications: Recommendations for Authors," by R. D. Weiner, L. A. Weaver, Jr., and H. A. Sackeim, *Convulsive Ther* 1988;4:88-91. Copies of the recommendations are available from the Editorial Office.

References: The authors are responsible for the accuracy of the references. Key the references (double-spaced) at the end of the manuscript. Cite the references in text in the order of appearance. Cite unpublished data—such as papers submitted but not yet accepted for publication and personal communications, including e-mail communications—in parentheses in the text. If there are more than three authors, name only the first three authors and then use et al. Refer to the *List of Journals Indexed in Index Medicus* for abbreviations of journal names, or access the list at <http://www.nlm.nih.gov/tsd/serials/lji.html>. Sample references are given below:

Journal article

1. Farkas LG, Tompson B, Phillips JH, et al. Comparison of anthropometric and cephalometric measurements of the adult face. *J Craniofacial Surg.* 1999;10:18-25.

Book chapter

2. Todd VR. Visual information analysis: frame of reference for visual perception. In: Kramer P, Hinojosa J, eds. *Frames of Reference for Pediatric Occupational Therapy*. Philadelphia, PA: Lippincott Williams & Wilkins; 1999:205-256.

Entire book

3. Kellman RM, Marentette LJ. *Atlas of Craniomaxillofacial Fixation*. Philadelphia, PA: Lippincott Williams & Wilkins; 1999.

Software

4. *Epi Info* [computer program]. Version 6. Atlanta, GA: Centers for Disease Control and Prevention; 1994.

Online journals

5. Friedman SA. Preeclampsia: a review of the role of prostaglandins. *Obstet Gynecol* [serial online]. January 1988;71:22-37. Available from: BRS Information Technologies, McLean, VA. Accessed December 15, 1990.

Database

6. CANCERNET-PDQ [database online]. Bethesda, MD: National Cancer Institute; 1996. Updated March 29, 1996.

World Wide Web

7. Gostin LO. Drug use and HIV/AIDS [JAMA HIV/AIDS Web site]. June 1, 1996. Available at: <http://www.ama-assn.org/special/hiv/ethics>. Accessed June 26, 1997.

Figures:

A) Creating Digital Artwork

1. Learn about the publication requirements for Digital Artwork: <http://links.lww.com/ES/A42>
2. Create, Scan and Save your artwork and compare your final figure to the Digital Artwork Guideline Checklist (below).
3. Upload each figure to Editorial Manager in conjunction with your manuscript text and tables.

B) Digital Artwork Guideline Checklist

Here are the basics to have in place before submitting your digital art:

- Artwork should be saved as TIFF, PDF, Word Doc, PPT, or EPS files.
- Artwork is created as the actual size (or slightly larger) it will appear in the journal. (To get an idea of the size images should be when they print, study a copy of the journal to which you wish to submit. Measure the artwork typically shown and scale your image to match.)
- Crop out any white or black space surrounding the image.
- Diagrams, drawings, graphs, and other line art must be vector or saved at a resolution of at least 1200 dpi. If the art is created in an MS Office program, convert to a hi-res PDF. If the PDF creation process is unfamiliar then submit the MS Office doc.
- Photographs, radiographs and other halftone images must be saved at a resolution of at least 300 dpi.
- Photographs and radiographs with text must be saved as postscript or at a resolution of at least 600 dpi.
- Each figure must be saved and submitted as a separate file. Figures should not be embedded in the manuscript text file.

Remember:

- Cite figures consecutively in your manuscript.
- Number figures in the figure legend in the order in which they are discussed.
- Upload figures consecutively to the Editorial Manager web site and number figures consecutively in the Description box during upload.

Figure legends: Include legends for all figures. They should be brief and specific, and they should appear after the text and before the references. Use scale markers in the image for electron micrographs, and indicate the type of stain used.

Color figures: The journal accepts for publication color figures that will enhance an article. Authors who submit color figures will receive an estimate of the cost for color reproduction. If they decide not to pay for color reproduction, they can request that the figures be converted to black and white at no charge.

Tables: Create tables using the table creating and editing feature of your word processing software (e.g., Word, WordPerfect). Do not use Excel or comparable spreadsheet programs. Do not submit tables as image files (e.g., TIFF, JPG, EPS). Submit each table in a separate file. Cite tables consecutively in the text, and number them in that order. Each table should appear on a separate sheet and should include the table title, appropriate column heads, and explanatory legends (including definitions of any abbreviations used). Do not embed tables within the body of the manuscript. They should be self-explanatory and should supplement, rather than duplicate, the material in the text.

Style: In general, style should be patterned after the *American Medical Association Manual of Style* (9th edition). *Stedman's Medical Dictionary* (27th edition) and *Merriam Webster's Collegiate Dictionary* (10th edition) should be used as standard references. Drugs and therapeutic agents should be referred to by their accepted generic or chemical names. The name should not be abbreviated. Code numbers should be used only when a generic name is not yet available. In that case, the chemical name and a figure giving the chemical structure of the drug is required. Copyright or trade names of drugs should be capitalized and placed in parentheses after the name

of the drug. Names and locations (city and state in USA; city and country outside USA) of manufacturers of drugs, supplies, or equipment cited in a manuscript are required to comply with trademark law and should be provided in parentheses. Units of measure should be expressed in the metric system, and temperatures should be expressed in degrees Celsius. Conventional units should be written as SI units as appropriate.

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Supplemental Digital Content (SDC): Authors may submit SDC via Editorial Manager to LWW journals that enhance their article's text to be considered for online posting. SDC may include standard media such as text documents, graphs, audio, video, etc. On the Attach Files page of the submission process, please select Supplemental Audio, Video, or Data for your uploaded file as the Submission Item. If an article with SDC is accepted, our production staff will create a URL with the SDC file. The URL will be placed in the call-out within the article. SDC files are not copy-edited by LWW staff, they will be presented digitally as submitted. For a list of all available file types and detailed instructions, please visit <http://links.lww.com/A142>.

SDC Call-outs

Supplemental Digital Content must be cited consecutively in the text of the submitted manuscript. Citations should include the type of material submitted (Audio, Figure, Table, etc.), be clearly labeled as "Supplemental Digital Content," include the sequential list number, and provide a description of the supplemental content. All descriptive text should be included in the call-out as it will not appear elsewhere in the article.

Example:

We performed many tests on the degrees of flexibility in the elbow (see Video, Supplemental Digital Content 1, which demonstrates elbow flexibility) and found our results inconclusive.

List of Supplemental Digital Content

A listing of Supplemental Digital Content must be submitted at the end of the manuscript file. Include the SDC number and file type of the Supplemental Digital Content. This text will be removed by our production staff and not be published.

Example:

Supplemental Digital Content 1.wmv

SDC File Requirements

All acceptable file types are permissible up to 10 MBs. For audio or video files greater than 10 MBs, authors should first query the journal office for approval. For a list of all available file types and detailed instructions, please visit <http://links.lww.com/A142>.

After Acceptance

Page proofs and corrections: Corresponding authors will receive electronic page proofs to check the copyedited and typeset article before publication. Portable document format (PDF) files of the typeset pages and support documents (e.g., reprint order form) will be sent to the corresponding author by e-mail. Complete instructions will be provided with the e-mail for downloading and printing the files and for faxing the corrected page proofs to the publisher. Those authors without an e-mail address will receive traditional page proofs. It is the author's responsibility to ensure that there are no errors in the proofs. Changes that have been made to conform to journal style will stand if they do not alter the authors' meaning. Only the most critical changes to the accuracy of the content will be made. Changes that are stylistic or are a reworking of previously accepted material will be disallowed. The publisher reserves the right to deny any changes that do not affect the accuracy of the content. Authors may be charged for alterations to the proofs beyond those

required to correct errors or to answer queries. Proofs must be checked carefully and corrections faxed within 24 to 48 hours of receipt, as requested in the cover letter accompanying the page proofs.

Reprints: Authors will receive a reprint order form and a price list with their page proofs. Reprint requests should be faxed to the publisher with the corrected proofs, if possible. Reprints are normally shipped 6 to 8 weeks after publication of the issue in which the item appears.

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APPENDIX 2.2

NHS Lanarkshire Research & Development Approval

NHS Lanarkshire Research & Development: Amendment Approval Letter

Project I.D. Number L13101_GE59



Miss Claire Stewart
Trainee Clinical Psychologist
Administration Building
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date	30 January 2014
Enquiries to	Elizabeth Mcgonigal, R&D Facilitator
Direct Line	01236 712459
Email	Elizabeth.Mcgonigal@lanarkshire.scot.nhs.uk

Dear Miss Stewart

Project title: Older adults' experience of electroconvulsive therapy and post-ECT support: An interpretive phenomenological analysis

R&D ID: L13101_GE59

NRS ID NUMBER: NRS14/MH125

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire

As you are aware, NHS Lanarkshire has agreed to be the Sponsor for your study. On its behalf, the R&D Department has a number of responsibilities; these include ensuring that you understand your own role as Chief Investigator of this study. To help with this we have outlined the responsibilities of the Chief Investigator in the attached document for you information.

All research projects within NHS Lanarkshire will be subject to annual audit via a questionnaire that we will ask you to complete. In addition, we are required to carry out formal monitoring of a proportion of projects; in particular those projects that are Sponsored by NHS Lanarkshire. In either case, you will find it helpful to maintain a well organised Site File. You may find it helpful to use the folder that we have included for that purpose.

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.



- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.show.scot.nhs.uk/cso/> or the Research & Development Intranet site: <http://firstport/sites/randd/default.aspx>).
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

c.c.

NAME	TITLE	CONTACT ADDRESS	ROLE
Raymond Hamill	Corporate R&D Manager	R&D Department Corporate Services Building Monklands Hospital Monkscourt Avenue Airdrie ML6 0JS	Sponsor Contact



Dr Leigh Whitnall	Acting Consultant Clinical Psychologist	NHS Lanarkshire East Kilbride CMHT for Older People Aitholl House 1 st Floor Churchill Avenue East Kilbride G74 1LU	Named Contact
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c.c – (email) nhs@nhscc@nhs.net

Enc: 1 x Site File
1 x Responsibilities as Sponsor Notes

APPENDIX 2.3

NHS Ayrshire & Arran Research & Development Approval



Research & Development
58 Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Miss Claire Stewart
Trainee Clinical Psychologist
East Kilbride CMHT for Older People
Atholl House, 1st Floor
Churchill Avenue
East Kilbride
G74 1LU

Date 30 January 2014
Your Ref
Our Ref AG/KLB/NM R&D 2014AA005
Enquiries to Karen Bell
Extension 25850
Direct line 01563 825850
Fax 01563 825806
Email Karen.bell@aaaht.scot.nhs.uk

Dear Miss Stewart

***Older adults' experience of electroconvulsive therapy (ECT) and post-ECT support:
An interpretive phenomenological analysis***

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Approved documents:

Document	Version	Date
SSI form	Version 3.5	20/12/13 signed
Protocol	Version 4.0	25/10/13
R&D Form	Version 3.5	20/12/13 signed
Participant Consent Form	Version 1.0	10/13
Participant Information Sheet	Version 2.0	12/13
Participant Invitation Letter	Version 2.0	12/13
Staff Information Sheet - NHS	Version 2.0	12/13
Interview Schedule	Version 1.0	10/13

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

- Miss Claire Stewart, Trainee Clinical Psychologist, NHS Lanarkshire

With additional investigator: -

- Dr Salma Iqbal, Clinical Psychologist in Older Adults/Local NHS Psychology Tutor, NHS Ayrshire and Arran

The sponsors for this study are NHS Lanarkshire.

This approval letter is valid until 30 June 2015.

Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- **Device storage and transportation complies with our policy 'Secure Storage, Communication and Transportation of Personal Information' and in particular Section 8 of that policy (attached).**
- All research activity must comply with the standards detailed in the Research Governance Framework for Health and Community Care www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.
- Recruitment figures must be submitted to R&D on a monthly basis. If recruitment figures are not received timeously you will be contacted by a member of the R&D team to provide this data.
- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at www.ich.org/LOB/media/MEDIA482.pdf), Ethics Guidelines, Health & Safety Act 1999 and Data Protection Act 1998.
- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.
- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.
- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.
- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collated in line with NHS Scotland IT Security Policies, until the destruction of these data. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at Ailsa Hospital 01292 513693 or 513694).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely



Dr Alison Graham
Medical Director

c.c.
Dr John Taylor, Associate Medical Director, Mental Health Services, University Hospital Crosshouse
Dr Joan Barber, Consultant Old Age Psychiatrist, Ayrshire Central Hospital
Raymond Hamill, R&D Office, NHS Lanarkshire (sponsor contact)
Dr Hamish McLeod, Academic Supervisor, University of Glasgow
Dr Kenneth Mullen, Academic Supervisor, University of Glasgow
Dr Nasim Rasul, Consultant Old Age Psychiatrist, Ailsa Hospital
Cathy Kyle, Consultant Clinical Psychologist, Ailsa Hospital
Lesley Douglas, Finance, Ailsa Hospital
Information Governance, Ailsa Hospital
NRS Coordinating Centre, Aberdeen

www.nhsaaa.net



APPENDIX 2.4

West of Scotland Research Ethics Approval

WoSRES
West of Scotland Research Ethics Service



Miss Claire Stewart
Trainee Clinical Psychologist
Mental Health and Wellbeing
Administration Building
University of Glasgow, Gartnavel Royal Hospital,
1055 Great Western Road
Glasgow
G12 0XH

West of Scotland REC 5
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 8NT

Date 20 December 2013

Direct line 0141 211 2102
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Miss Stewart

Study title: Older adults' experience of electroconvulsive therapy (ECT) and post-ECT support: An interpretive phenomenological analysis.
REC reference: 13/WS/0298
IRAS project ID:

Thank you for your letter of 15 December 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair and Lead Reviewer.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Sharon Macgregor, WoSREC5@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rctforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	1.0	October 2013
Investigator CV		
Letter of invitation to participant	2	December 2013
Other: Supervisor CV (McLeod)		
Other: Supervisor CV (Whitnall)		
Participant Consent Form	1.0	October 2013
Participant Information Sheet	2	December 2013
Participant Information Sheet: SEAN Co-ordinator	2	December 2013
Participant Information Sheet: Staff	2	December 2013
Protocol	4	25 October 2013
REC application		31 October 2013
Referees or other scientific critique report		21 October 2013
Response to Request for Further Information		15 December 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.bra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



for
Dr Gregory Ofili
Chair

Enclosures: "After ethical review – guidance for researchers"

Copy to: Raymond Hamill, NHS Lanarkshire

APPENDIX 2.5

Staff Information Sheet

Title of study: Older adults' experience of electroconvulsive therapy (ECT).

Chief Investigator:

Claire Stewart (Trainee Clinical Psychologist)

Research Supervisors:

Dr Leigh Whitnall (Acting Consultant Clinical Psychologist)

Dr Hamish McLeod (Clinical Psychologist)

Dr Kenneth Mullen (Senior University Teacher)

This information sheet has been given to you as you are an Old Age Psychiatrist, ECT nurse practitioner, or clinician in the older adult Community Mental Health Team in Lanarkshire or Ayrshire & Arran. I would like to ask you to take a few minutes of your time to read over this information sheet.

This sheet is designed to give you all the information that you will require to understand the study and identify patients who may want to participate. I have tried to answer any obvious questions that you may have, but if you would like to discuss any aspect of the study further, please do not hesitate to contact me.

Background and Purpose

I am training to be a Clinical Psychologist and attend the University of Glasgow for teaching. I also work within NHS Lanarkshire. As part of my training I am conducting this research project to help clinicians gain a better understanding of people's experiences of ECT and how to support them.

What is the study about?

ECT is a controversial treatment, and most studies that have attempted to investigate patients experiences of ECT have used quantitative methods which fail to capture the richness and complexity of a patient's experience. Qualitative methods can be employed to explore in detail how patients are making sense of their experience and the meaning that the experience holds. Previous qualitative studies have identified feelings of fear, powerless and concerns about memory loss, but have not investigated how people make sense of their experience and what factors assist them in this process. The current study focuses on how older adults make sense of their experience of ECT, what helped them to do this, or what got in the way of doing this. I also want to see whether ECT has changed the way they see themselves. Additionally, I am interested in what people found valuable about the follow-up sessions that are sometimes available after receiving ECT.

Currently, there is no research investigating older adults' experiences of ECT. I am interested in understanding how older adults' experience ECT as research shows those over 65 in developed countries receive a disproportionately high share of ECT compared with younger adults. Additionally, there may be differences between younger and older adults' experiences of ECT due to factors such as cohort effects, developmental stage, greater emotional complexity and greater life experience.

Who is eligible to take part?

Patients who have received ECT at least 6 months ago, but no longer than 5 years ago are being asked to take part. Participants who are eligible to participate will be:

- Aged over 65 years of age,
- English speaking (due to interviewer and interpreter constraints).

Patients will be excluded from participation if they:

- Present with symptoms of moderate to severe dementia (indicated by score of 82 or below on ACE-III) or significant mental health difficulties which impact upon their functioning,
- Have significant verbal communication difficulties.

What do I need to do?

If you know of an individual who meets the criteria for the study, please provide them with the enclosed participant information sheet. If the patient is interested in participating, please ask for their contact details and consent for me to contact them to discuss the study. Alternatively, please provide my contact details to allow them to contact me (these are detailed at the end of the participant sheet).

I will then arrange an appointment for the interviews at a convenient time and at an NHS location within their locality. When we meet I will ask them to sign a consent form to show that they have read and understood the information provided to them and that they agree to take part in the study.

Do patients have to take part?

No, patients do not have to take part and deciding not to take part will not affect their care in any way. Even if they do decide to take part, they can withdraw from the study at any point if they change their mind.

What will happen to the participant information?

The interviews will be recorded. The recordings will be transcribed, anonymised then destroyed. The anonymous transcripts will be stored on an encrypted password protected computer. Only my supervisor (a psychologist working for the University) and I will have access to the recordings. The information will be analysed and presented in the form of a report and submitted to the University of Glasgow in part fulfilment of Doctorate in Clinical Psychology and for publication in a scientific journal. Within the report, anonymous quotes of what participants have said may be used. Participants will be provided with a summary of the results if they wish.

Are there any benefits to participants taking part?

There are no direct benefits to the participant for taking part in this study. However, the information that is provided may contribute to our understanding of how people experience and make sense of ECT. If this study is published in a scientific journal, it would contribute to the wider research literature and could contribute to developments in the psychological care and support of patients undergoing this treatment.

Are there any down sides to participants taking part?

It is possible that the discussions may trigger upsetting thoughts or feelings that may be difficult for the participant to talk about. If this is the case, and the participant wishes to stop, they can end the interview at any time. If they need a break during the interview this can be arranged.

Who has reviewed the study?

The study has been approved by the University of Glasgow, the National Research Ethics Committee and the NHS Lanarkshire and NHS Ayrshire & Arran Research and Development Teams.

What if something goes wrong?

We do not anticipate any harms or risks from taking part in this study. However, if you have any concerns or complaints regarding the way this research has been conducted or the way you have been tested, you can contact us at any time.

Thank you for taking the time to read this Staff Information Sheet and for any further input you may wish to have.

Claire Stewart, Trainee Clinical Psychologist
Mental Health and Wellbeing,
The University of Glasgow,
Gartnavel Royal Hospital,
1055 Great Western Road,
G12 0XH

Email: c.stewart.3@research.gla.ac.uk

Telephone: 07867 372519

APPENDIX 2.6

Participant Information Sheet

Title of study: Older adults' experience of electroconvulsive therapy (ECT).

Chief Investigator:

Claire Stewart (Trainee Clinical Psychologist)

Research Supervisors:

Dr Hamish McLeod (Clinical Psychologist)

Dr Kenneth Mullen (Senior University Teacher)

This leaflet has been given to you by a Clinician involved in your mental health treatment, on behalf of Claire Stewart (Trainee Clinical Psychologist). You are being invited to take part in a research study.

Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part.

Background and Purpose

I am training to be a Clinical Psychologist and attend the University of Glasgow for teaching. I also work within NHS Lanarkshire. As part of my training I am conducting this research project to help clinicians gain a better understanding of people's experiences of ECT and how to support them.

What is the study about?

I am interested in hearing about how older adults make sense of their experience of ECT, what helped them to do this, or what got in the way of doing this. I also want to see whether ECT has changed the way they see themselves. Additionally, I am interested in what people found valuable about the follow-up sessions that are sometimes available after receiving ECT.

Why am I being asked to take part?

You are being asked to take part because you are over 65 years old and have received ECT.

Do I have to take part?

No, you do not have to take part and deciding not to take part will not affect your care in any way. Even if you do decide to take part, you can withdraw from the study at any point if you change your mind.

What would I have to do?

If you do decide to take part, you will be invited to an interview at an NHS building near where you live. You will be asked to sign a consent form. The interviews are expected to last for about 60 minutes. The interviews will be recorded. You will only need to meet with the researcher on this one occasion to participate.

Who would know I was taking part?

The clinician who initially spoke to you about taking part in the study would know that you were taking part, but the information that you provided would be made anonymous so that no one would be able to identify you. I would need to know your name and date of birth to be able to inform the team that you are taking part. I would only discuss what you told me with someone out with the research team if you told me anything that made me think that you were at risk of harm. In these circumstances, I would need to share my concerns but I would tell you before I did this.

What will happen to the information I provide?

The interviews will be recorded. The recordings will be transcribed, made anonymous then destroyed. The anonymous transcripts will be stored on an encrypted password protected computer. Only my supervisors (psychologists for the University) and I will have access to the recordings. The information will be presented in the form of a report and submitted to the University of Glasgow as part of a Doctorate in Clinical Psychology and will be published in a scientific journal. Within the report, anonymous quotes of what you have said may be used. You will be provided with a summary of the results if you wish.

Are there any benefits to taking part?

There are no direct benefits to you for taking part in this study. However, the information that you provide will help our understanding of how people experience and make sense of ECT. It will allow us to work out how best to support people who have had ECT. If this study is published in a scientific journal, it would contribute to the wider research literature and could contribute to developments in the psychological care and support of patients.

Are there any down sides to taking part?

It is possible that our discussion may trigger upsetting thoughts or feelings that may be difficult for you to talk about. If this is the case, and you wish to stop, you can end the interview at any time. If you need a break during the interview this is okay.

What if something goes wrong?

We do not anticipate any harms or risks from taking part in this study. However, if you have any concerns or complaints regarding the way this research has been conducted or the way you have been tested, you can contact us at any time.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. The study has been approved by the University of Glasgow, the National Research Ethics Committee and the NHS Lanarkshire and NHS Ayrshire & Arran Research and Development Teams.

What do I do now?

If you are interested in taking part in the study, please speak to the person who gave you this information sheet who will pass on your contact details to me. I will then telephone you to answer any questions that you may have about the study and arrange an appointment for the interview at a time when you can attend. You can also contact me directly using the details below if you would rather. When we meet I will ask you to sign a consent form to show that you have read and understood the information provided to you and that you agree to take part in the study.

Thank you for taking the time to read this Participant Information Leaflet and for any further input you may wish to have.

Claire Stewart, Trainee Clinical Psychologist
Mental Health and Wellbeing,
The University of Glasgow,
Gartnavel Royal Hospital,
1055 Great Western Road,
G12 0XH

Email: c.stewart.3@research.gla.ac.uk

Telephone: 07867 372519

APPENDIX 2.7

Participant Consent Form

Title of Study: Older adults' experience of electroconvulsive therapy.

Name of Chief Investigator: Claire Stewart (Trainee Clinical Psychologist)

Please initial the box

1. I confirm that I have read and understood the information sheet dated Oct 2013 (version 1.0) for the above study. ☐
2. I have had a chance to discuss this study and ask questions. ☐
3. I have received satisfactory answers to all of my questions. ☐
4. I have received enough information about the study. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that my interview will be recorded on a digital voice recorder and transcribed, and I give permission for this. ☐
7. I understand that only Claire Stewart and the supervising Psychologist (University of Glasgow) will have access to the personal information that I provide. ☐
8. I understand that some of what I say may be used as a quote when the study is written up, and I consent to this. ☐
9. I agree to take part in the above study ☐

If, when the study is finished, you would like to receive a short summary of the study findings please write your postal address below.

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Participant Consent Form Version 1 (23/08/2013)

1 copy to researcher, 1 to participant, 1 to hospital records.

APPENDIX 2.8

Interview Schedule

Introduction

Thank you for agreeing to attend this interview today, I really appreciate you giving up your time to speak to me about your experience of Electroconvulsive Therapy. Just before we start, I'd like to go over a few bits of paperwork. Firstly, I just need to make sure that you know why you have come along today and that you are still ok to go ahead with the interview. I understand that (*referring clinician's name*) gave you information about the study and that you read the participant information sheet? Did you understand everything in that document? (*If no, clarify information, if yes present consent form*) Then I would just like to go through this consent form with you. If you agree with the statements listed, then tick the box next to it. Once you are finished, sign the bottom of the page.

Now I would just like to ask a couple of questions about the circumstances that lead to you receiving ECT before we start the interview.

- | | | |
|------------------------------------|-------|----|
| 1. Did you see a psychiatrist? | Yes | No |
| 2. Did you receive a diagnosis? | Yes | No |
| a. If yes, what was the diagnosis? | _____ | |
-
1. My first question focuses on how having ECT has affected you.
 - How did you feel directly after having your ECT?
 - How did you feel longer term after having ECT?
 - Thinking about before and after ECT, do you notice anything different about yourself?
 2. When we have experiences, good or bad, we tend to think about them and try to make sense of them and understand them. How have you made sense of your experience of ECT?
 - What has helped you to do this?
 - What has gotten in the way of doing this?
 3. Sometimes experiences can affect the way that we see ourselves and what we think about ourselves. Has ECT affected the way you see yourself?

- Do you see yourself in a better/worse light?
4. Were you offered any sessions after your treatment by nurses or another clinician?
- If so, proceed to question 5, if not then proceed to question 6.
5. What was your experience of the post-ECT support sessions?
- Did you find them helpful?
 - Do you think there is a need for these sessions?
 - If you did find them helpful, what did you value about the sessions?
 - What do you think it may have been like after ECT without these sessions?
 - Could they be improved in any way?
 - Do you think these sessions made it easier for you after ECT?
6. What would you have thought of the opportunity to have a session with someone after your ECT?
- Do you think this would have been helpful?
 - If so, what do you think would have been helpful about it?

That is the end of the interview. Thank you very much for coming along today and talking about your experience of ECT. What will happen now is that I will analyse the data and product a report. It will all be anonymous and if you have said on your consent form that you would like a copy, I will send you one when it's finished. Thank you again.

APPENDIX 2.9

Sample of coded interview transcripts

Appendix 2.9.1 - Key to transcripts

Descriptive comments focus on describing the content of what the participant has said, the subject of the speech within the transcript (underlined).

Linguistic comments focus on exploring the specific use of language by the participant (**bold**).

Conceptual comments focus on engaging at a more interrogative and conceptual level (*italic*).

Samples of coded interview transcripts - 'Judith'

Emergent themes	Original transcript	Exploratory comments
<p>Desperation to get well</p> <p>Involved in the decision to have ECT</p> <p>She had power/knowledge/control</p> <p>Desperation to get well</p> <p>Her choice for ECT</p> <p>ECT fixed me</p>	<p>(hometown) and she said I think you should have more serious treatment, so she said I could come here [mental health ward]. Well, I was prepared to do anything to feel better because life was so awful, so I was in the ward and saw Dr 1 and got more treatment, more antidepressants, different ones but they didn't seem to help. And come the end of April last year, I saw Dr 1 and he said, he suggested ECT, and I thought, well things aren't any better, I mean I was getting plenty visitors, I've a lot of friends in (organisation), over the years I've been the chair, the secretary, and am still on the committee, and still very productive in (organisation), I'm not boasting, I'm just saying these are facts..</p> <p>Int: yeah but you had that, life beforehand, so it's really unusual for you to feel this low and to feel...</p> <p>Pt: I wanted a different kind of, I didn't want to feel my life had ended and there was nothing, and I knew somewhere out there was a better life and so when Dr 1 suggested ECT and more of less explained it, I thought "well, I will go ahead", and I think I started the first ECT in April, twice a week, and the last one was at the end of may, and I had 9 ECT sessions all together here, and I began to feel better from the second or third one.</p>	<p>'serious treatment' – things bad <u>Prepared to do anything to feel better</u> 'life so awful' – emphasising how low she felt</p> <p><u>More antidepressants but they didn't help</u></p> <p><u>Dr suggested ECT. A sense that she considered his suggestion of ECT, and was involved in the decision?</u></p> <p><i>Again illustrating her productivity? Capability? Very important for her to be seen this way (sense of identity that's important to her)</i></p> <p><u>She didn't want to feel her life had ended</u> 'life ended', 'nothing', - emptiness, finality, lack of hope? <u>Had hope there was a better life, wanted to get there</u> Dr 1 suggested – ultimately it was her choice though? 'more of less explained it' – explanation lacking? <i>She feels it was her decision to have ECT 'I will go ahead'</i> <i>Proving her memory is still good? A lot of detail.</i> <u>She began to feel better from the 2nd or 3rd session of ECT. Quite clearly attributing her improvement to the ECT? That's what made her better?</u></p>

Samples of coded interview transcripts - 'Anne'

<p>Others had control</p>	<p>Pt: really for about 5 or 6 years uh-huh</p> <p>Int: and then at the tail end of 2013, no 2012 it would have been, the beginning of 2013, your mood started to go down again and you had another bout of ECT in July 2013.</p> <p>Pt: yes, now I don't know how long it took to, eh, to have the first treatment, like from being admitted, I forget that part, cos as I say, I don't remember much at all about the first 2 weeks. I didn't even realise I'd had the treatment, you know, but as I said, (husband) consented straight away at that point</p> <p>Int: cos he'd seen the effects of last time?</p> <p>Pt: uh-huh, he remembered how it had really helped.</p> <p>Int: and how did you feel when you started to realise you were having ECT again? Do you remember what you were thinking about that?</p> <p>Pt: emmm, I felt, oh dear, a wee bit sad at times that it had happened again and eh, "was this the only way out?" But eh, I began to get more positive because I felt "no, it's something that helps you" and I was beginning to think along that, sort of, way.</p> <p>Int: what was that bit of sadness about do you think? What was making you sad about having to get it again?</p>	<p>Seems muddled, confused due to sentence structure ad use of um's, eh's and ah's</p> <p><u>Didn't realise she'd had it</u> <i>Someone else (husband) deciding for her</i></p> <p><u>Husband consented as he knew how much it helped her last time</u></p> <p>'oh dear' – sadness? Despair? <u>Felt sad it had happened again</u> <i>Hadn't been expecting it to happen again? Feelings of sadness/failure at this?</i> <i>Again, 'only way out' – last resort, only option available? Arguing with herself, initially feeling down about 'having to have ECT' but then answering with – 'but it helps you'. Accepting that although don't like the idea of it, it's a helpful treatment and it works for her?</i></p>
<p>Others had control</p> <p>ECT fixed me</p> <p>ECT as a last resort</p> <p>Depression as an external entity</p> <p>Just part of the treatment</p>		

APPENDIX 2.10

Superordinate themes, sub-themes and supporting evidence

Table 2: Superordinate themes, sub-themes and supporting evidence

Superordinate theme (SOT)	Sub-themes (ST)	Participant Extracts used	Total extracts per ST	Total extracts per SOT
Experience of depression	As if it's two different folk	Anne (n=2)	3	8
		Mary (n=1)		
	It must have been some chemical alteration	Judith (n=2)	5	
		Mary (n=1)		
		Anne (n=1)		
Maggie (n=1)				
Power and control	The decision was not really mine	Anne (n=2)	6	10
		Judith (n=2)		
		Mary (n=1)		
		Maggie (n=1)		
	What exactly are these electrodes doing to me?	Mary (n=2)	4	
		Maggie (n=1)		
		Judith (n=1)		
Changing beliefs about ECT	I would do anything just to be back to normal	Judith (n=2)	7	27
		Anne (n=2)		
		Mary (n=2)		
		Maggie (n=1)		
	Oh yes, there was a fear before	Mary (n=2)	5	
		Maggie (n=1)		
		Judith (n=1)		
		Anne (n=1)		
	And you did it, and that was it	Maggie (n=1)	4	
		Mary (n=1)		
		Anne (n=1)		
		Judith (n=1)		
	I think it possibly gave me a wee jolt	Mary (n=2)	11	
Maggie (n=2)				
Judith (n=4)				
Anne (n=3)				

APPENDIX 2.11

Major Research Project Proposal

Older adults' experience of electroconvulsive therapy: An interpretive phenomenological analysis.

Matriculation Number: 1103926

Version Number: 4

Word Count: 3, 190

Abstract

Background: Electroconvulsive therapy (ECT) is prescribed in cases of severe and treatment resistant depression. Its efficacy in reducing depressive symptoms is well established but it remains one of the most controversial treatments in psychiatry. The opinions of patients undergoing ECT are rarely examined, and studies that have investigated this are conducted with younger adults using quantitative methods that may obscure the expression of complex attitudes. **Aims:** The present study aims to investigate older adults' experiences of ECT and post-ECT psychological support using a qualitative methodology. The focus will be on how they make sense of their experience, what helped or hindered them in doing this, the extent that they integrate this into their life narrative, and any impact on their sense of self. **Methods:** Six to eight older adults (over 65 years of age) who have experienced ECT will be recruited using purposive sampling. Semi-structured interviews will be conducted, transcribed, and analysed using Interpretative Phenomenological Analysis (IPA). **Applications:** Investigating older adults' experiences of receiving ECT and post-ECT follow-up sessions will inform psychologists about what factors are important to people undergoing this experience. This will give them the opportunity to consider how post ECT support could be designed to facilitate adjustment and reduce any long-term psychological impact of ECT.

Abstract word count: 208

Introduction

Electroconvulsive therapy (ECT) is prescribed in cases of severe and treatment resistant depression (American Psychiatric Association, 2001). Many studies have shown that for patients resistant to medication, ECT shows fast and effective results with 85 – 90% efficacy compared to 60 – 65% efficacy for antidepressant medication (Nobler & Sackeim, 2001; Shergill & Katona, 2001). Despite this, ECT remains one of the most controversial and misunderstood treatments in psychiatry. One of the main concerns repeatedly raised in relation to ECT is whether it permanently damages cognitive functioning. Studies measuring cognition post-ECT generally indicate that detrimental effects on concentration, sustained attention, orientation, the retention of newly learned information and the retention of information learned before treatment tend to resolve by 3 to 6 months following treatment completion (Squire, 1986; Lisanby et al., 2000).

Although the preservation of all aspects of cognitive functioning are likely to be important to patients, preservation of memory, specifically autobiographical memory, is likely to be particularly salient. Autobiographical memory refers to memories of events from a person's own history, and has been linked to the development of problem solving skills, facilitation of social interactions and relationships, establishment of a coherent self-identity and development of emotional resilience (Bluck et al., 2005). Given the functions of autobiographical memory, it is not difficult to appreciate that impairment in this domain may be of particular personal importance to patients. However, the effect of ECT on the ability to recall autobiographical information remains unclear. For example, Calev et al. (1991) reported an initial impairment in autobiographical memory, but performance improved after one month and actually exceeded pre-ECT levels by six month follow up. However, some studies have found that difficulties remain. Kho et al. (2006) found that those who had been treated with ECT and pharmacotherapy showed significantly greater problems in recalling

personal memories than those who had received pharmacotherapy alone. However, patients were not randomised to treatment group, so differences in recall could be associated with pre-existing differences between samples, for example, severity of depression (Fraser et al., 2008). Sackeim et al. (2007) conducted a large-scale, community based study and concluded that some forms of ECT have substantial deficits in performance on tests of autobiographical memory; both immediately following ECT and at six month follow up. Consistent with this, Weiner et al. (1986) also reported autobiographical memory deficits that were still present up to six months after ECT.

In addition to research on the cognitive effects of ECT, most research to date has focused on investigating aspects of ECT such as efficacy, dosage, administration and mechanism of action. This is valuable information and has revolutionised the administration of ECT, however, the subjective experiences of patients undergoing ECT have rarely been evaluated (Chakrabarti, Grover & Rajagopal, 2010). Research throughout the 1980's and early 1990's that did attempt to address this, (Freeman & Kendall, 1980; Malcolm, 1989; Riordan et al., 1993) asked patients to respond to questions or complete checklists about their attitudes to and experience of ECT. These studies found that most people appear to find ECT helpful; most people report side-effects (around 80% in most studies), with memory impairment the most frequent complaint; and most people report that ECT is not frightening to receive. The results of these studies would seem to support Freeman & Kendall's (1980) conclusion that patients find ECT a helpful treatment and not particularly frightening. However, these studies have used quantitative approaches, attempting to categorise experiences and attitudes by comparing frequency of positive and negative answers, which Rose et al (2003) argue does not allow complex attitudes and opinions to be described. Rose, Fleischmann and Wykes, (2004) propose that people's beliefs about their experiences and their social world are complex, and that reducing patients' perspectives on ECT to simple measurements of attitude does not capture the richness and complexity of experience. They recommend that

qualitative methods are employed to explore in detail how patients are making sense of their experience and the meaning that the experience holds.

Although limited in number, some qualitative research has focused on investigating patients' experiences of ECT. Johnstone (1999) found that for certain patients, ECT is a lasting traumatic experience. Her sample focused on those who reported having found ECT an upsetting experience, and she uncovered themes including feelings of fear, shame and humiliation, worthlessness and helplessness, and a sense of having being abused and assaulted. Surveys from service user run organisations have also identified several psychological after-effects including loss of confidence, dignity and self-esteem; fear of hospitals and psychiatry; anger and aggression; loss of self; and nightmares (UKAN, 1996). Rose et al. (2003) found that patient led studies report lower rates of satisfaction with ECT compared to clinician led studies. They argue that clinician studies tend to take place too soon after treatment, use medical assessors in clinical settings and use brief questionnaires with low complexity for responses. By analysing articles with patients' views after treatment with ECT, they found that at least a third of patients report significant memory loss after treatment, and that routine neuropsychological tests used to assess memory do not address the types of memory loss reported by patients. In a recent review of clinician and service-user led research, Fisher (2012) concluded that the experience of ECT was not a neutral one, and that patients are actively making sense of their experiences before, during and after ECT. He identified that some patients may experience psychological reactions to the treatment, including fear, feelings of powerlessness and concerns about memory loss. He reflected that all of these can impact on identity and sense of self.

As can be seen, ECT is a controversial treatment. One of the main concerns raised by patients and those opposed to the treatment are the potential cognitive side effects. Research to date suggests that any detrimental effects on most aspects of cognitive

functioning tend to resolve within 6 months. However, this does not appear to be the case for autobiographical memory (Verwijk et al., 2012). Autobiographical memory is drawn on to assist us in making sense of our experiences. This process of “making sense” allows us to develop a narrative which, according to narrative theory, can be defined as an organised interpretation of a sequence of events that allows us to make sense of an ever changing world, and to define ourselves and our identity (Murray, 1999). Narrative has increasingly assumed greater importance in the social sciences as it is argued that we are born into a storied world and that we live our lives through the creation and exchange of narratives (Murray, 1999). Despite this, there is little research exploring the complexities of the sense people make of their experience of ECT and the meaning it holds for them. Studies that have attempted to investigate this have focused on younger adults and some have identified feelings of fear, powerless and concerns about memory loss. Others report that ECT is not frightening to receive and is helpful. However, many of these studies have used quantitative methods which may not be capturing the richness and complexity of patient experiences. Currently, there is no research investigating older adults’ experiences of ECT. It is important to understand how older adults’ experience ECT as research shows those over 65 in developed countries receive a disproportionately high share of ECT compared with younger adults (Chanpattana, 2007; Wood & Burgess, 2003; Department of Health, 1999). Studies have consistently estimated that 24% to 50% of patients receiving ECT are older adults (Chanpattana 2007). Additionally, there may be differences between younger and older adults experiences of ECT due to factors such as cohort effects, greater emotional complexity and greater life experience. Cohort differences are based on maturing in a specific historical time period, and those from specific cohorts have different skills, values, and life experiences than those from other cohorts. Developmental maturation leads to greater emotional complexity and a wealth of life experience upon which to draw, which will impact on attitudes and beliefs. Additionally, one of the main developmental tasks of later life is to review life and integrate experiences into a coherent and meaningful narrative. This will

likely mean that any disruption to this may have more salience to older adults than to younger ones. The high prevalence of chronic medical problems in this population is also likely to have influenced individuals' attitudes and opinions regarding medical practitioners and medical procedures. All of these factors may influence older adults' attitudes to and experiences of ECT, and lead to differences between this population and younger adults.

Aims and Research Questions

Aims

The present study has two aims:

1. To investigate older adults' experiences of receiving ECT, specifically how they make sense of their experience, what helped or hindered them in doing this, the extent that they integrate this into their life narrative, and any impact on their sense of self.
2. To investigate older adults' experiences of receiving post-ECT support if this was available, specifically whether this support was valued, and if so, what aspects were valued.

Plan of Investigation

Design

Qualitative research focuses on understanding how people make sense of their world and the experiences they have in the world (Merriam, 2009). Specifically, Interpretative Phenomenological Analysis (IPA) explores how individuals make sense of their personal and social world in order to understand the meanings they attach to specific experiences (Smith & Osborn, 2003). The goal of IPA is to investigate participants' perceptions of their social world by maintaining as far as possible, an insider's view of the phenomenon being explored (Smith and Osborne, 2003). Therefore, IPA is not interested in producing an objective record

of an event, but is concerned with the way in which people think about an event. As such, it seems an appropriate tool for use in the current study to interpret semi-structured interviews designed to explore individuals' experiences of ECT and the post-ECT support they received from the psychology service.

Participants

In accordance with IPA methodology, purposive homogeneous sampling will be used. This involves selecting participants because they have particular features or characteristics that will enable detailed exploration of the phenomena being studied, rather than selecting a randomised sample. Therefore, patients will be eligible to participate if they:

- Are over 65 years of age,
- Are English speaking (due to interviewer and interpreter constraints),
- Have received ECT at least 6 months ago, but no longer than 5 years ago

Patients will be excluded from participation if they:

- Present with symptoms of dementia (indicated by score of 88 or above on the Addenbrooks Cognitive Examination-III),
- Present with mental health difficulties which significantly impact upon their functioning, and would prevent them from participating in an interview (determined by the clinical judgement of the clinician referring them to the study)
- Have verbal communication difficulties that would prevent them from participating in an interview (determined by the clinical judgement of the clinician referring them to the study)

Justification of sample size

The aim of IPA is to analyse the perceptions and understandings of a particular group in detail, and as such, studies are conducted on small sample sizes (Smith & Osborne, 2008).

Smith and Osborne (2008) state that sample size depends on the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the constraints the researchers are working under. Smith et al., (2009) advise those undertaking professional doctorates to interview between four and ten participants. Taking this information into consideration, it is estimated that between six and eight participants will be recruited.

Recruitment Procedures

Old Age Psychiatrists, ECT nurse practitioners, and clinicians in the older adult Community Mental Health Teams (CMHT's) in Lanarkshire and Ayrshire will be provided with information about the study by the principal researcher (see Appendix 4). These clinicians will be asked to identify patients on their caseload that meet the inclusion criteria and approach them to see if they would be interested in participating. A letter of invitation to participate in the research will also be sent to eligible patients who no longer attend the service. Additionally, information about the study will also be provided to The Scottish ECT Accreditation Network's (SEAN)'s Clinical Coordinator, who acts as liaison between SEAN and a service user group. The clinical coordinator will be asked to approach a service user group, and ask those who meet the inclusion criteria if they would be interested in participating. Permission will also be sought for the principal researcher to visit the service user group and deliver a short presentation about the study. The participant information sheet (see Appendix 5) will be left for those interested in finding out more about the study.

In all of these scenarios, those interested in participating will be provided with a participant information sheet containing further details of the study and the contact number and email address for the principal researcher (see Appendix 5). Permission will also be sought for the principal researcher to contact them. If this consent is obtained, contact details will be recorded by the clinician or the clinical coordinator and passed to the principal researcher.

Potential participants will be contacted by the principal researcher. All potential participants will be offered a telephone consultation or face to face meeting to address any questions or concerns they have about participating, before being asked to give consent to participate in the study. Once a participant has agreed to take part, written consent will be obtained (see Appendix 6) and an appointment will be arranged to conduct the interview. It will be made clear at all stages of recruitment and testing that participants can choose to withdraw from the study at any time.

Research Procedure

Once consent has been received, participants will be invited to attend an interview session to complete a semi-structured interview lasting around 45 minutes. The interview will consist of a range of open-ended questions, including prompts that allow further elaboration of the topic under discussion if required (see Appendix 7). Participants will be offered a break and it will be made clear that they may withdraw from the study at any time. Verbal consent will be sought before beginning the interview. Interviews will be held in an outpatient psychiatry clinic room on NHS premises within the participants' locality. This is likely to be more convenient for participants and reduce travel time and costs. As the topic of investigation has the potential to be emotive, the principal researcher will monitor participants' emotional reactions throughout the interview and use clinical experience and skills to respond appropriately to any distress. The principal researcher has experience of discussing highly emotive issues and managing distress, and it is anticipated that the interview proposed will not illicit more distress than would be found in normal clinical practice. Should a participant become distressed, the principal researcher will remain with them until their distress reduces. If distress does not reduce, the participant will be advised to attend their GP. Participants will also be offered a de-briefing session with an appropriate and identified clinician after the interview. Full permission will be obtained to use verbatim quotations in the write-up of the study.

Data Analysis

The interviews will be recorded, transcribed verbatim and anonymised, with patient identifying information removed. Once transcribed, recordings will be deleted. The transcriptions will be stored on an NHS password protected encrypted laptop. IPA will be employed to analyse the transcripts. This methodology consists of a number of stages. Firstly, a transcript will be read thoroughly and repeatedly, allowing the principal researcher to become familiar with the account. Initial coding will allow ideas to be summarised, and then recurrent themes can be extracted, with key words or phrases acting as codes. This procedure will then be repeated for each transcript. Reading the subsequent transcripts, the principal researcher will identify repeated patterns while still allowing additional topics to be identified (Smith & Osborn, 2003). Thematic connections will then be identified within and across transcripts. Finally, the themes will be clustered and developed into a list of master or subordinate themes. To validate inter-rater reliability of the themes identified, a secondary rater (research supervisor or peer) will independently rate a random selection of transcripts.

Settings and Equipment

Participants will be interviewed within NHS premises in Lanarkshire or Ayrshire & Arran, which have clearly defined procedures in place regarding clinical appointments. See Appendix 2 for details of equipment needed.

Health and Safety Issues

Interviews will be conducted in older adult psychiatry clinic rooms in an NHS building within participants' locality. Interviews will be carried out within normal working hours and abide by the standard NHS guidelines for interviewing patients.

Written consent will be obtained from participants and they will be made aware of their right to withdraw from the study at any time. Although there is a chance that the interviews may illicit distressing emotions, this is not expected to be any more distressing than those emotions elicited in normal clinical practice. The interviewer will also be experienced in managing and monitoring emotional state. All participants will have the opportunity to discuss their experience of participation and debrief with the researcher. If there is any evidence of distress the researcher will suspend the interview and will stay with the participant until their distress decreases. If they remain distressed, other means of accessing emotional support will be discussed with the participant, such as contacting a family member or GP. To minimise fatigue it will be made clear to participants that breaks are available throughout the interview.

Ethical Issues

Ethical approval will be sought from the appropriate research ethics committee. The project will also be registered with NHS Lanarkshire and NHS Ayrshire & Arran's Research and Development Department. Participants will be provided with a standard patient information sheet detailing the requirements and purpose of the study. A telephone or face to face consultation will be offered to all participants before informed consent is obtained to provide an opportunity to ask questions and address concerns about the study. Written consent will be obtained from all participants. Participants will not be coerced into participating in the study, and they will have the option to withdraw their consent at any time. Patient identifiable information will be removed during transcription, and interview recordings will be deleted. Data will be stored in accordance with the Data Protection Act (1998) and NHS policy.

Timetable

Date	Task
September 2013	Proposal submitted
October 2013	Approval letter from Research Director
Late October 2013	Submit project for ethical approval
December 2013	Hope to receive ethical approval
January 2014	Commence recruitment
February/March 2014	Complete recruitment
March – May 2014	Analysis of interviews
May - June 2014	Write up research
July 2014	Submit final copy (inc. systematic review)

Practical Applications

Exploration of older adults' experiences of ECT will add to the developing literature regarding the attitudes and emotions patients experience receiving this treatment. It has been reported that at least some patients experience adverse psychological reactions to ECT, including fear, feelings of powerlessness and concerns about memory loss. Further investigation into how an older adult makes sense of their experience, and whether there is an impact on their sense of self following treatment will provide useful information to psychologists when thinking about how to support patients. Investigating older adults' experiences of receiving post-ECT follow-up sessions and analysis of what aspects of this were valued, will also allow psychologists the opportunity to provide input into the design of these sessions. It is hoped this information will inform service delivery and uncover ways to reduce the longer-term psychological impact of ECT.